

THE UNIVERSITY OF ALBERTA

CONCEPT MAPPING WIVES ADAPTATION TO
HUSBANDS WITH BRAIN INJURIES

BY

Karima Lacène



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in partial fulfillment of the requirements for the degree of

MASTER OF EDUCATION
IN
COUNSELLING PSYCHOLOGY

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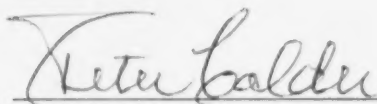
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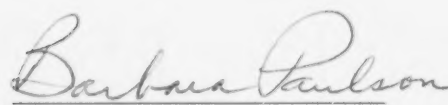
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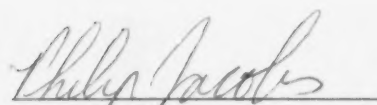
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The undersigned certify that they have read, and recommend to the Faculty of
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submitted by **KARIMA LACÈNE** in partial fulfillment of the requirements for the
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Dated: *June 28, 1996*

DEDICATION

To my wonderful son Troy,
who fills my life with inspiration and joy.

Abstract

The present study conceptualizes the process of adaptation of women following their husband's brain injuries. The Concept Mapping Method was employed to analyze the qualitative data obtained from an investigation by Ford (1993). In response to the first open-ended question, "How has your husband's brain injury affected you?", ten themes are generated including positive attitude to self, confidence/independence, responsibilities, resentment/frustration, stress/support issues, loss issues, family adaptation, marital/communication difficulties, dependency issues, and verbal/physical abuse. In response to the second open-ended question, "How have you dealt with your husband's brain injury?" seven themes are generated including coping via distractions, time for self, patience/open mind, counselling/support groups, family/friends support, family cohesiveness, and supportive nurturing role. The themes could serve as the basis for the development of individual and group support counselling programs for the spouses of brain injured individuals.

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CHAPTER 1 - INTRODUCTION

The purpose of this study was to conceptualize the process of adaptation of women following their husband's brain injuries employing the Concept Mapping technique. The present study analyzed the qualitative data obtained from an investigation by Ford (1993), entitled Wives Adaptation to Husbands with Brain Injuries. More specifically, the qualitative data obtained from the two open-ended questions asked during the telephone interviews are objectively analyzed using the Concept Mapping Method.

In Canada, it is estimated 200 cases per 100,000 population require hospitalization each year as a result of traumatic brain injury (Parkinson, Stephenson, & Phillips, 1985). The incidence rate for strokes, another major cause of brain injury not considered in the traumatic brain injury statistics, is estimated at 250 per 100,000 population (Alberta Health, 1991). Using this incidence figure, Alberta experiences approximately 4860 new cases per year requiring hospitalization (Alberta Health, 1991). The increased efficiency of the emergency health care system and the effectiveness of neurosurgical techniques have improved the likelihood that individuals who sustain severe brain injury will survive. These individuals, are often left with permanent mental and physical impairments and may, depending on the severity of their injury, never return to their former lifestyle. Statistics show the tremendous ramifications, personal and societal, of brain injury, and concomitantly, highlight the need for programs and research to address the needs of this special population (DeJong et al., 1990).

The investigation of spousal adaptation following brain injury can help direct researchers to develop new areas for intervention and for the development of individual counselling and group support programs. In addition, understanding the impact of an individual's disability on spousal adaptation can add to the growing empirical literature on traumatic brain injury and family dynamics.

Definition and Classification of Brain Injury

Brain injuries can be broadly classified as either traumatic brain injuries or "other types" of brain injuries that can result from a wide variety of causes including aneurysms, arteriovenous malformations, tumors, blood clots, and surgical interventions.

Traumatic brain injuries are defined as damage to living brain tissue that is caused by an external mechanical force. Traumatic brain injuries are most often caused by motor vehicle accidents, falls (domestic), industrial-related accidents, recreation-related accidents, motorcycle-related accidents, and assaults. Brain injury can result from either open or closed head injury (Richardson, 1990). In open head trauma, there is injury to the scalp and the skull is actually broken, either as a result of penetration or from the effects of the force used. Closed head injury is often caused by a blunt object hitting the skull, causing, in some cases, the skull to pull away from the brain, or in other cases, causing the skull to be crushed inward without breaking. The skull remains intact without obvious external damage. In both types of trauma a brain injury may occur. The effects may be chronic or acute, but will depend on the specific area, location of injury,

and most importantly on the extent of not only primary damage, but also secondary damage to brain tissue.

The actual brain damage can be caused by tissue compression, tension, shearing or a combination of these mechanisms. This compression at the site of impact tears and bruises nerve fibres and is termed a contusion. Certain areas of the skull, most notably the base of the frontal and temporal lobes, have bony ridges that enhance the likelihood of a contusion at these sites. There are two categories of traumatic brain injury: primary and secondary damage. Primary damage, which occurs instantaneously (Pang, 1989), includes skull fractures, contusions of the gray matter and diffuse white matter lesions (Smith, 1985). Secondary damage which occurs is causally related to primary damage, and includes swelling, intercranial hematoma, cerebral hypoxia (Smith, 1985). Therefore, damage is caused, not only to the primary trauma site, but also may be diffuse and more wide-ranging because of other factors such as shearing and hemorrhaging that can further damage the brain. These combine to produce a great deal of variability in physical, cognitive and psychosocial impairments and recovery (Sohlberg & Mateer, 1989).

Brain injuries are often characterized by a period of altered consciousness (amnesia or coma) that can be as brief as a few minutes or long as many years. The resulting tissue damage can impair an individual's physical, mental, or psychosocial abilities (Vogenthaler, 1987). The most common consequences of brain injuries can include the following: short and long-term memory loss, decreased learning ability and

diminished ability to think and reason, decreased ability to concentrate, inappropriate behavior, lack of initiative and motivation, fluctuating levels of mood and emotion, difficulty in communicating, and physical disabilities (Dring, 1989).

The severity of brain injuries is most commonly determined by the depth of coma as measured by the Glasgow Coma Scale (GCS) and the period of unconsciousness or posttraumatic amnesia (PTA). The GCS is a 13 point scale, ranging from 3 through 15, divided into three categories of neurological responsiveness: eye opening, verbal responses, and motor responses (Teasdale & Jennett, 1974). Brain injuries are generally classified as mild, moderate, or severe. The term "mild" has typically been used to define brain injuries in which the period of unconsciousness is relatively short (fewer than 20 minutes), there is no known structural damage to the skull or brain, and GCS scores range from 13 to 15. Moderate brain injuries are usually defined as a GCS score of 9 to 12 and a loss of consciousness of between 20 minutes and 24 hours. Severe brain injuries are most often defined as a GCS score of 3 to 8 and a loss of consciousness of greater than 24 hours. The focus of research in recent years has shifted away from the severe end of the brain injury spectrum with the realization that approximately 90% of all brain injuries are classified as mild or moderate in severity (Gouver, 1986).

Stoffles (1988) reports that many persons with brain injury may experience impairments in the areas relating to psychosocial functioning. These include: fatigue, mood swings, denial, self-centeredness, agitation, anxiety, depression, poor self-monitoring, emotional lack of control, sexual dysfunction, restlessness, lack of

motivation, inability to cope, excessive laughing or crying, and difficulties relating to others.

The Effects of Brain Injuries on Wives

Researchers and clinicians in the field of traumatic brain injury note repeatedly that the family plays a crucial role in the physical, cognitive, and vocational rehabilitation of the brain-injured person (Kreutzer, Gervasio, & Camplair, 1994). Apparently traumatic brain injury has an adverse effect on family functioning and family satisfaction (Rosenbaum & Najenson, 1976). This is probably due to the lengthy process of recovery and the sudden alteration of the brain-injured person's abilities. The stressors imposed upon family members may reduce their own abilities to maintain vocational or household responsibilities and to facilitate the patient's rehabilitation. Mauss-Clum and Ryan (1981) suggest that patients with strong family support progress further than those without family involvement.

There is a growing literature on the role of the family members and their reaction to traumatic head injury (Jacobs, 1989). Rehabilitation literature has noted that when one member of the family becomes disabled all members of the family must cope with the effects (Trieschmann, 1980). Families serve as the major source of support, socialization, and assistance for the person with traumatic brain injury (Jacobs, 1989). Thomsen (1974) and Livingston, Brooks, and Bond (1985) stress the need for comprehensive long-term treatment and support for both the individual with the brain injury and family members. Dring (1989) suggests that the family plays an important role in the rehabilitation process

by either encouraging rehabilitation or retarding rehabilitation and causing severe psychological and economic strain on the family.

Lezak (1988) describes the emotional and practical burden felt by the primary caretaker of a person with traumatic brain injury. The impact can be particularly traumatic for a spouse who may be forced to give up their jobs or other pursuits to see that the disabled family member receives the best care and treatment in the home or elsewhere. Lezak notes that caretakers are likely to experience significant depression within the first year after the head injury. A limited number of studies have attempted to investigate the variables involved in the adaptation process of wives of men with brain injuries (Ford, 1993; Kreutzer, Gervasio & Camplair, 1994). Ford (1993) investigated the relationships among six variables related to the adaptation of wives of men who had sustained brain injuries. These variables included the levels of psychosocial functioning of the husbands as reported by their wives and the wives' levels of subjective burden, dyadic adjustment, social support, coping, and well-being. Another study investigated the prevalence of psychological distress and unhealthy family functioning among primary caregivers of persons with traumatic brain injury (Kreutzer et al., 1994).

Concept Mapping Method

Concept mapping is a set of statistical methods that can be used to cluster variables into their underlying themes. Kunkel (1993) suggests that concept mapping methods can lead to a greater understanding of the perceptual themes underlying psychological disorders. He states that concept mapping can add objectivity to the study

of qualitative types of data that have typically been analyzed using non-statistical approaches.

Concept mapping also allows for the study of constructs as they are experienced by participants rather than as defined by researchers (Daughtry & Kunkel, 1993). Consequently, this approach to the analysis of qualitative data allows confidence in the results because of the inherent objectivity in these methods. The development of concept maps of wives adaptation to husbands with brain injuries may prove useful for the assessment and/or development of treatment programs. A further advantage of the concept mapping method is that it allows the data to be grouped by many sorters. This reduces the potential for influence or subjectivity that can be present when qualitative data are sorted and grouped by an individual researcher. Concept maps can also assist in the communicating of important concepts clearly and easily. Finally, concept maps can provide direction for future research.

Research Questions

In order to gain a better understanding of the experiences of women married to men with brain injuries, three research questions were examined utilizing the Concept mapping technique. These are as follows:

1. What are the effects on women who have brain injured husbands?
2. How do women deal with the effects of their husbands' brain injuries?
3. Once identified, do these effects fall into any themes or categories that help define them and give meaning to the role they may play in the adaptation process?

Organization of Thesis

This thesis is organized in five chapters. The first chapter provides an introduction and overview to the study. Chapter Two provides a review of the literature related to variables associated with wives adaptation to husbands with brain injuries. In addition, a review of the concept mapping literature is presented.

Chapter 3 outlines the methods and criteria for the selection of women participating in the study. The procedure for data collection and the self-report measures employed are described. In addition, the methods of data analysis are presented.

In chapter 4 the results of the investigation are presented in two sections. An analysis of the qualitative data previously collected from Ford's (1993) study is discussed. Section A describes the set of statements derived from the interrater agreement process for the first research question. Next the results of the multidimensional scaling and the cluster analysis will be discussed to explain the concept map for question one. This phase of the study attempted to identify themes within which these statements might fall. The results of Section A are discussed and related to previous research. Section B describes the set of statements derived from the interrater agreement process for the second research question and the concept map for question two. Moreover, the results of Section B are discussed and related to findings in the literature.

Chapter 5 is a general discussion and an overall summary of the findings. Results from both research questions are summarized and placed within the context of the literature presented.

In addition, the limitations of the study are described, implications for practice are discussed, and some directions for future research are outlined.

CHAPTER 2 - REVIEW OF THE LITERATURE

Introduction

The following chapter describes the literature relevant to factors related to wives' adaptation to their husbands brain injuries. These variables include stress, the psychosocial functioning of the husbands, subjective burden experienced by the wives, personality changes, marital adjustment, resources, social support, and coping. In addition, an overview of the concept mapping methodology is presented.

Factors related Wives adaptation to brain injured husbands

Stress

A review of the literature related to the stress experienced by close relatives of individuals with brain injuries indicates that the level of stress is often assumed to be related to the severity of the brain injury (Peters, Stambrook, Moore, Zubek, Dubo, & Blumenschein, 1992). However, numerous researchers have demonstrated that mild and moderate levels of brain injuries can have as deleterious a consequence as severe injuries for injured individuals and their family members (Alves, 1989; Binder, 1986; O'Shaughnessy, Fowler, & Reid, 1984; Rimel, Giordani, Barth, Boll, & Jane, 1981; Stuss, Ely, Hugenholtz, LaRochelle, Poirier, & Bell, 1985).

A recent study investigated the prevalence of psychological distress and unhealthy family functioning among primary caregivers of 62 adult outpatients with traumatic brain injury (Kreutzer, Gervasio, & Camplair, 1994). Approximately half of the caregivers

reported elevated distress as indicated by scores on the BSI General Stress Index. Spouses were significantly more likely to report elevated depression scores compared to parents.

McCubbin and McCubbin (1991) suggest that because family crises evolve and are resolved over a period of time, families seldom deal with only a single stressor. Rather, families experience what they describe as a "pile up of demands", particularly from chronic stressors such as caring for a disabled family member or a major role change for one member. McCubbin and McCubbin (1991) identify five broad types of stressors and strains that contribute to a "pile up" in the family system (a) the initial stressor and its hardships; (b) normative transitions; (c) prior strains; (d) the consequences of family efforts to cope; and (e) ambiguity, both intra-family and social. McCubbin and McCubbin (1991) describe normative transitions as including the normal growth and development of family members and of extended family and family life cycle changes. In terms of prior strains, Pearlin and Schooler (1978) suggest that families experience ongoing strains that may be the result of unresolved hardships from earlier stressors or transitions or the result of present roles. When a new stressor is experienced by the family these prior strains are exacerbated and contribute to the stress of the crisis. In terms of efforts to cope, McCubbin and McCubbin (1991) suggest that additional stressors may emerge from certain behaviors that family members use in order to cope with the crisis. For example, returning to work in order to provide financial support for the family may cause additional stress for the woman. In terms of intra-family and social

ambiguity McCubbin and McCubbin (1991) suggest that a certain amount of ambiguity is inherent in every crisis, since change and the demand for adaptation create uncertainty about the future.

Brooks et al. (1986) interviewed the caretakers of individuals with traumatic brain injury five years post injury. Caretakers reported significantly greater levels of stress when compared to one year post injury. This suggests that factors other than the individual's symptoms account for the caretaker's stress. The authors suggest that with the passage of time family members may develop a greater intolerance for the individual's limitations.

Psychosocial functioning of the husbands

Several investigators in the area of brain injuries suggest that the most consistent and, on a long-term basis, the most disabling consequences of brain injuries are the impairments in what can be termed "psychosocial functioning" (Hendryx, 1989; Jennett, Snoek, Bond, & Brooks, 1981; Mauss-Clum & Ryan, 1981; McKinlay et al., 1981; Oddy, Humphrey, & Uttley, 1978a, 1978b; Weddell, Oddy, & Jenkins, 1980). Psychosocial functioning encompasses behavioral and emotional sequelae (irritability, self-centeredness, lack of initiative, mood swings, impulsivity, restlessness, anxiety, and depression) as well as cognitive difficulties (poor concentration and forgetfulness). Several authors have documented the social consequences of such sequelae including marital breakdown, unemployment, and social isolation (Oddy, Coughlan, Tyerman, &

Jenkins, 1985; Oddy et al., 1978a, 1978b; Thomsen, 1984). It has been suggested that it is these psychosocial deficits which have the greatest relevance in terms of the stress experienced by the partner.

Liss and Willer (1990) suggest that typical problems of individuals who have sustained severe traumatic brain injuries include difficulties with attention and concentration, planning, impulsivity, communication, memory and information processing, and judgement and perception. Willer, Liss, and Arrigali (1989) examined the problems and coping strategies of individuals with traumatic brain injuries and their spouses. Able-bodied wives reported that the biggest problems were the personality changes of their husbands, their husbands' lack of insight into their disabilities, and the role performance changes in companionship, child rearing, and financial support. Willer, Allen, Liss, and Zicht (1991) found that wives of individuals with brain injuries identified changes in the personalities of their husbands as their greatest problem, followed by cognitive difficulties encountered by their husbands, their husbands' lack of insight and acceptance of their disabilities, the reduction in income, and the loss of emotional support and companionship they had previously received from their husbands. Women with children expressed concerns regarding the effects on their children of having fathers with brain injuries.

Several investigators contend that head injury may be a potentially useful factor in explaining some types of aggressive behavior (Rosenbaum, & Hoge, 1989; Rosenbaum, Hoge, Adelman, Warnken, Fletcher & Kane, 1994; Warnken, Rosenbaum, Fletcher,

Hoge, & Adelman, 1994). Warnken et al., 1994, suggest that head-injured males are at increased risk for physical aggression in their intimate relationships.

Subjective burden experienced by the wives

Researchers have begun to examine the main features of psychosocial burden as perceived by the relatives of individuals with brain injuries (Allen , Linn, Gutierrez, & Willer, 1994; Brooks & Aughton, 1979; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981).

Allen et al., (1994) investigated burden experienced by 60 spouses and 71 parents who served as primary caregivers to individuals with traumatic brain injury. Overall, both parents and spouses of individuals with traumatic brain injury exhibited high levels of burden. Relative to spouses, parents reported significantly greater burden related to lifespan care. Spouses reported significantly less personal reward than did parents. The presence of social aggression and cognitive disability in the individual with brain injury was found to have a greater association with subjective burden of caregivers than was the presence of physical disability or injury severity.

One source of burden is the family's concern for the future care of the individual with traumatic brain injury (Oddy, Humphrey, & Uttley, 1978). Jacobs (1987) reports that long term financial issues were a source of concern for all caretakers.

Another source of burden for caretakers is the lack of social interaction and associated feelings of isolation following severe head injury. The individual's behavioral changes become obstacles to effective social interaction and are related to decreases in friendships (Jacobs, 1989).

Brooks and McKinlay (1983) found that the association between the injured individuals' personality changes and the relatives' burden increases over time. Over a one year period the relatives showed a decreasing ability to accept, and cope with, negative changes in the injured individuals' behaviors.

Livingston, Brooks, and Bond (1985) found that high self-rating of burden continued in the relatives of severely injured individuals throughout the year following injury. They found that distress in the relatives seemed to be associated more with day to day symptomatic complaints than with the initial severity of injury.

Rosenbaum and Najenson (1976) studied married couples in which the husbands were Israeli soldiers who were disabled by traumatic brain injuries. This study compared the burden and reactions of wives of soldiers with traumatic brain injuries to those of wives of men with spinal cord injuries. The results demonstrate that, while both groups of wives experienced considerable stress during the first year following injury, greater stress was experienced by the wives of the men with brain injuries. The spouses of men with brain injuries reported decreased leisure time, fewer contacts with friends, and greater disruption of their marital relationships. They also felt less able to share household, childrearing, and financial responsibilities with their now disabled husbands.

Personality Changes

Simpson (1991) investigated changes in personality in head injured individuals one or more years postinjury and marital relationships. Participants were 18 males and 3 females who had sustained a moderate degree of brain impairment, and their respective spouses. Results confirmed that head injured subjects evidenced significant personality changes. Further, their self perceptions of their personality characteristics were significantly different from their spouses' perceptions. Both head injured subjects and spouses were significantly less happy in their marriages subsequent to the head injury. In addition, spouses were more likely to identify specific sources of conflict in their relationships and less likely to describe their marriages in socially desirable terms than head injured subjects. This is consistent with the findings of another study which examined the level of agreement between head injured individuals and their relatives (McKinlay & Brooks, 1984). They found systematic differences between the responses, with the highest amount of disagreement for behavioral and emotional characteristics.

Marital Adjustment

Various studies have investigated the effects of brain injuries on the marital relationship. Liss and Willer (1990) reviewed research regarding the effects of traumatic brain injuries on marital relationships. Their findings demonstrate that spouses' reactions to traumatic brain injuries include feelings of anxiety, isolation, and loss.

Bond (1984) observed that wives of older men with traumatic brain injury are more likely to stay with their husbands. Younger, more recently married couples may be less able to cope with the increasing pressures. Thomsen's (1989) 15 year follow up data indicate that there may be a higher level of marital separation when compared to the general population. Of the 40 subjects in Thomsen's study, nine were married at the time of the injury. At the 15 year follow-up period only two of these couples had remained together.

Jennett (1990) suggests that for individuals with brain injuries who are married, these marriages frequently break down under the stress of brain damage. Peters, Stambrook, Moore, & Esses, (1990) suggest that the marital relationships of individuals with brain injuries are vulnerable to stress, that the wives of individuals with severe brain injuries experience distress following the injuries, and that they perceive high levels of burden imposed by the injuries.

Jacobs (1989a) reports that marital separation and divorce and family discord are higher among family members of individuals with traumatic brain injuries, as compared to the general population. Jacobs suggests that changes in marital status may be related to the ongoing difficulties of living with the effects of brain injuries. The stress of living with the effects of brain injuries is compounded by the lack of support normally provided by one's partner.

The behavioral effects of head injury often include personality changes for the injured individual. Spouses frequently observe that the individual is no longer the same

as the person they married (Earnes & Wood, 1989). The spouse may also change in response to the increasing challenges of dealing with the effects of a brain injury (Jacobs, 1989). The stress of these changes may lead to deterioration in the marital relationship.

Maitz (1990) investigated the impact of severe closed head injury on the family system and marital relationship. The results indicate the loss of family cohesion in the head injury couples is crucial in that it compromises the family's ability to respond to crises, and may contribute to the high rate of divorce in these families.

Kravetz et al. (1995) investigated the influence of a man's brain injury on both his and his wife's self-concept and perception of marital vulnerability. Marital vulnerability of the wives of husbands with brain injury was lower than the control group. Both men with brain damage and their wives exhibited a decrease in self-esteem and an increase in conflict and pathology.

Lezak (1988) discussed several clinical observations of the effects of brain injuries on spouses. She notes that spouses live in "social limbo," because they do not have a partner to participate in the many social activities that are couple-oriented, and they are not free to find new partner. It is difficult for spouses to work through the feelings surrounding mourning and loss, because society does not recognize the feelings of loss when a loved one's personality changes. If the marriage was satisfactory before the injury, feelings of responsibility, guilt, and fear of social condemnation may add to the reluctance of spouses to divorce their injured partners. Lezak (1988) also suggests that when a partner in a stable marriage sustains a severe head injury, their spouse loses a

close companion, and one of their major sources of emotional support and affection, at a time when this support is most needed.

The behavioral and physical ramifications of traumatic brain injury may effect the sexual relationship. Spouses' sexual desires may become frustrated (Lezak, 1988). Another study investigated the psychosexual sequelae of closed head injury (O'Carroll, Woodrow & Maroun, 1991). The results indicated that of the 36 patients, 50% of male patients with current sexual partners produced psychosexual profiles that fell within the dysfunctional range.

Resources

The social, behavioral and personality changes associated with these injuries often produce dramatic changes in the family system, family members relinquish and redefine family roles (Maitz, 1990).

McCubbin and McCubbin (1991) identify as separate variables in their model of family adjustment and adaptation, several different aspects of a family's resources. They emphasize two major sets of capabilities (a) resources and strengths, which are what the family has and (b) coping behaviors and strategies, which are what the family does as individual members in the family unit and what the family does collectively as a family unit. Furthermore, McCubbin and McCubbin (1991) consider there to be three potential sources of resources (a) individual family members, (b) the family unit, and (c) the community. These researchers define an adaptive resource as a characteristic, trait or competency of one of these three sources. The first source of resources are personal

resources which include innate intelligence; knowledge and skills acquired from education, training, and experience; personality traits; physical and emotional health; a sense of mastery; and self-esteem. The second source of resources are family system resources which refer to characteristics or traits of the family system itself, that is, system qualities that make the family less vulnerable to stress and/or better able to withstand the impact of stressors and crises. Other family system resources include cohesion, adaptability, family organization, and communication skills. The third source of resources are community resources which include services from the government (medical and health care), schools, churches, and employers.

Social Support

The role of social networks in mediating the effects of stress is well established in the literature. Unger and Powell (1980), in their review of sociological and psychological studies, examined the strong positive relationship between social networks and a family's adaptation to societal crises, life transitions, and family conflicts. These researchers found that when families are in need of help they typically do not seek initial aid from formal organizations even if the organization is designed to serve the individuals presenting problem.

Vargo (1983) studied the adaptation to disability by the wives of men with spinal cord injuries. The presence of adequate, functional support systems was the single most important factor in the way in which these women reacted. When these support systems

were active and functioning well, the effect was positive; when they were absent or functioning poorly, the effect was negative.

There are numerous studies in the literature on caring for individuals with Alzheimer's disease which emphasize the importance of social support (Monahan, & Hooker, 1995; Aronson et al., 1984; Cantor, 1983; Gilhooley, 1984; Haley, Levine, Brown, & Bartolucci, 1987; Quayhagen & Quayhagen, 1988; Sistler, 1989). Zarit, Reever, and Bach-Petersen (1980) note that caregivers who received support from family and friends perceived less burden than caregivers who did not receive support. A recent study found a relationship between health outcomes of 51 spouse caregivers of dementia patients and personality and social support (Monahan & Hooker, 1995). George and Gwyther (1986), in their study of family caregivers of demented adults, indicate that 59% of the 510 caregivers surveyed expressed a need for more assistance from family and friends. Scott et al. (1986) report that socio-emotional support from family members is positively associated with more effective coping styles in Alzheimer's caregivers.

Liss and Willer (1990) suggest that caregivers have less time to restore their own social networks, which increases their degree of social isolation. This may be particularly problematic for a woman, who now may need someone other than her husband for support and companionship, but is limited by the time available to facilitate social contacts.

Zeigler (1989) investigated the importance of mutual support for spouses of head injury survivors. Topics discussed include role change with significantly increased

responsibility, economic changes, arrangements for care and/or supervision, the occurrence of unpredictable behavior, changes in the sexual relationship, and the use of mutual support or spouse support groups as a coping tool.

Coping

Kaplan, Smith, Grobstein, and Fischman (1973) studied coping with the stress imposed by a severe illness. They suggest that more must be learned about effective individual and family coping and more help given to improve this coping. A better understanding of the process of coping with severe stress would have substantial clinical and preventive value. Adaptive coping by the family and its individual members offers the greatest protection for family members confronted by stressful situations, and the best assurance that the family will continue as a unit, able to meet the changing needs of its members.

Coping with the impact of brain injuries is described in the rehabilitation literature as one of the most difficult tasks that can confront a family (Lezak, 1978; Oddy, 1984). Grinspun (1987) suggests that during the injured person's rehabilitation, considerable emphasis is placed on teaching family members about the nature of the injury and its consequences and assisting them in the coping process.

A few studies have investigated coping strategies employed by a close relative in relation to a family member with a brain injury. Klonoff and Prigatano (1987) conceptualize coping styles along two broad dimensions (a) functional/expected and (b)

dysfunctional. These researchers suggest that, in the former, despite the natural reactions of shock, sadness, and bitterness, the family eventually adapts to the existence of a relative with a brain injury.

Karpman, Wolfe, and Vargo (1985) explored, through indepth interviews, the process of psychological adjustment of the parents of 10 adults who had sustained brain injuries. Content analysis resulted in 12 themes, several of which can be viewed as "coping strategies," including maintaining a positive attitude; hope and optimism; a strong belief in religion; resistance, perseverance, and internal strength; cohesion and cooperation within the family; and an external support system. Karpman et al. (1985) conclude that additional studies are needed to empirically validate the themes derived in their study with other special needs groups and to implement and evaluate intervention programs aimed at assisting both injured individuals and their families with the process of adjustment.

Willer et al. (1991) report on the problems and coping strategies of individuals with traumatic brain injuries and their spouses. Their subjects included 20 men and 11 women with traumatic brain injuries and their respective spouses. All injured subjects had experienced severe head injuries one and a half years earlier. A structured small group discussion process was used to generate a list of problems and coping strategies. Individuals with traumatic brain injuries and their spouses identified problems in living as most important; loss of employment and restrictions on autonomy were reported as the most problematic. Men with traumatic brain injury placed priority on controlling their

anger, whereas, women with traumatic brain injury were concerned with their mood disorders, particularly depression. Women with traumatic brain injuries and able-bodied wives of men with brain injuries placed high priority on the use of support groups as a coping strategy. The coping strategies of women whose husbands had suffered brain injuries, in descending order of effectiveness were (a) a process of identifying problems in a realistic but optimistic manner, (b) becoming assertive in dealing with daily obstacles they encountered, (c) encouraging increased independence of their husbands, (d) getting away from family pressures and taking time for themselves, and (e) their own participation in support groups.

Adaptation of the Wives

McCubbin and McCubbin (1991) describe family adaptation as a concept which describes a continuum of outcomes that reflect efforts to achieve a balance at two levels of functioning (individual to family and family to community). McCubbin and Patterson (1983) describe the positive end of this continuum as bonadaptation and suggest that it is characterized by the maintenance and strengthening of family integrity, a continued promotion of individual member and family unit development, and the maintenance of family independence and a sense of control over environmental influences. The negative end of the continuum, family maladaptation, is characterized by deterioration of family integrity, a deterioration in an individual member's physical and/or psychological development, a deterioration in the quality of family relationships, and/or the loss or decline of family independence and autonomy.

In Vargo's (1983) study, 10 women, whose husbands had sustained spinal cord injuries after their marriage, were interviewed using an open-ended questionnaire format. Sixteen major themes emerged from the content analysis of the interviews. In relation to the process of adaptation, six factors emerged as being of primary importance to a satisfactory outcome including support systems, commitment to the marital relationship, hope, staff attitudes and advice, societal barriers, and children.

Statement of the Problem

Contemporary research has focused on theoretically driven constructs, with numerous scales to determine and measure the level of wives adaptation to their husbands' brain injuries (Ford, 1993).

It appears that no research has utilized the concept mapping method to identify the effects on women with brain injured husbands, and how women deal with these effects. Concept mapping is an alternative methodological approach combining qualitative and quantitative strategies which could complement the existing theory driven literature investigating this problem. In addition, analysis of these effects from general experiential data may assist with the future development of therapeutic techniques.

Concept Mapping

This section presents an overview of the concept mapping methodology. The process of adaptation of women following their husbands' brain injuries was examined in

this study using the concept mapping technique. Details of the study are presented in chapters four and five.

Concept mapping is a relatively new method of structured conceptualization which was developed by William Trochim (1989a) for use by groups in planning and evaluation. Typically, a six step process involving the planning of the study, the generation of statements, the structuring of statements, the representation of statements in the form of concept maps, the interpretation of maps, and the utilization of maps is followed (Trochim, 1989a).

There are two preparatory steps necessary before beginning the concept mapping process: choosing who will participate in the process, and deciding on the specific focus for the conceptualization (Trochim, 1989).

This is followed by the generation of a set of statements, about the research question. The statements can be generated through a brainstorming process, in which a selected group of subjects state in sentence form all the ideas regarding the research question (Trochim, 1989). The statements from all subjects are collected to redundancy. Following the removal of the redundant statements, the other statements are further reviewed and, if necessary, again reduced so there is a maximum of 100 statements.

In order to identify interrelationships between statements, it is necessary to perform a card sorting procedure on the set of statements. Each statement is printed on a separate index card and the cards are arranged in random order. Next, a group of sorting participants is chosen. The sorter is asked to sort the statements into groups having a

common theme or idea. The sets of grouped statements collected from the sorting participants are then analyzed using multivariate statistical techniques which include multidimensional scaling (MDS) and a cluster analytic technique. These analyses will identify common underlying conceptual categories through the generation of point and cluster maps, which emerge when item groupings determined by individual sorters are considered in combination (Trochim, 1989). Each group of statements, or themes, derived from the statistical analysis can be visually inspected and given a title, similar to naming factors in a factor analysis, which seems to describe the contents of that group. The final result is a map of the concepts developed in the analysis of the interrelationships among the sorted statements.

The concept map can be used for communication and educational purposes (Trochim, 1989). Each grouping can be viewed as a measurement construct and can be used to provide direction for future research. Moreover, the pictorial format of the actual map is likely to help people understand and retain the essential ideas more easily. Kunkel (1991) says that concept mapping can add objectivity to the study of more qualitative types of data that have typically been analyzed using non-statistical approaches.

A recent article describes the use of concept mapping to develop a conceptual framework of staff's views of a supported employment program for individuals with severe mental illness (Trochim, Cook, & Setze, 1994). In another study, concept mapping was used to assess community living and psychiatric hospitalization from a consumer/survivor perspective (Dumont, 1993). Valentine (1989) utilized the concept

mapping method to conceptualize caring in a nursing context. Linton (1989) describes the use of concept mapping to develop a framework for understanding the concept of feminism. Another investigation discussed how concept mapping was used to organize a conceptual framework from which a questionnaire was constructed, to evaluate the One-to-One Big Brother/Big Sister youth program (Galvin, 1989).

Although concept mapping was initially utilized largely by groups and committees for program planning and evaluation, it has been applied directly to the field of psychology. Recent research has been conducted in areas such as concept mapping the dysfunctional beliefs of battered women (Calder & Deby, 1992), concept mapping the problems of remarried families (Phillips, 1993), concept mapping the experience of depression (Daughtry & Kunkel, 1993), and concept mapping the beliefs of chronic low back pain sufferers (Knish, 1994).

Application to Current Research

It appears that no studies have been conducted using the concept mapping method to identify the process of adaptation of women following their husbands' brain injuries. Concept mapping also allows for the study of constructs as they are experienced by participants rather than as defined by researchers (Daughtry & Kunkel, 1993). Consequently, this approach to the analysis of qualitative data allows confidence in the results because of the inherent objectivity in these methods. The development of concept maps of wives adaptation to husbands brain injuries may prove useful for the assessment and/or development of treatment programs. A further advantage of the concept mapping

method is that it allows the data to be grouped by many sorters. This reduces the potential for influence or subjectivity that can be present when qualitative data are sorted and grouped by an individual researcher. Concept maps can also assist in the communicating of important concepts clearly and easily. Finally, concept maps can provide direction for future research.

CHAPTER 3: METHODOLOGY

The purpose of this study is to conceptualize the process of adaptation of women following their husbands' brain injuries employing the Concept Mapping technique. The concept mapping methodology represents an alternative approach that combines qualitative and quantitative research strategies. The present investigation analyzed the qualitative data previously collected from Ford's (1993) study. In her study, a telephone interview was conducted with each woman, in order to gather demographic and brain injury related information (Ford, 1993). In addition, these women were asked two open-ended questions regarding the effects of their husbands' brain injuries and the ways in which they had dealt with these effects.

Research Instruments

The telephone interview included two open-ended questions (a) Please list the ways (positive or negative) in which your husband's brain injury has affected you and (b) Please list the ways in which you have dealt with your husband's brain injury. From these two open-ended questions asked during the 62 telephone interviews, a total of 716 statements were collected. These statements are found in Appendix D of Ford's (1993) study. The first list includes 398 statement relating to the effects of their husbands' brain injuries (Question one) and the second list includes those statements which relate to the

ways in which the women dealt with their husbands' brain injuries and consists of 305 statements.

Subjects

The women who participated in Ford's study were selected on the basis of the following criteria: married to husband prior to his sustaining a brain injury, the husband was between the ages of 25 and 65, the brain injury occurred at least 1 year prior to the collection of data, the woman was living with husband at the time of data collection, and willingness to participate. The study underwent ethical review by the Department of Educational Psychology's ethics review committee, the Glenrose Rehabilitation Hospital's ethics review committee, and the Workers' Compensation Board's ethics review committee.

Interrater Agreement Process

Initially 62 telephone interviews were conducted and a total of 716 statements were recorded (Ford, 1993).

The statements from all subjects were reviewed, and those statements that were repetitious were removed. The raters consisted of the author and, a Ph.D. psychologist experienced in the area of concept mapping and head injuries. Following the removal of the redundant statements, the other statements were further reviewed by an interrater agreement process, and, were again reduced so there is a maximum of 80 statements. More than 100 statements has been found to be extremely difficult to sort into theme

groups (Trochim, 1989). Seventy-seven statements were transferred from Question 1 and eighty statements were transferred from Question 2, by the author from the transcribed interviews. The original statements were slightly modified to capture the essence of several similar statements.

Concept Mapping

Concept mapping is a structured conceptualization process which consists of three main components. First, ideas or statements are generated about a specific research question by a specified group of subjects. Second, the interrelationships between the ideas or statements are articulated by having a group of people sort the statements into sets containing a common theme. Multivariate statistical techniques are applied to this information to determine underlying categories. Finally, the concepts generated are depicted in the form of a picture or map which represents the ideas of interest (Trochim, 1989).

Preparation

There are two preparatory steps necessary before beginning the concept mapping process: choosing who will participate in the process, and deciding on the specific focus for the conceptualization (Trochim, 1989). Initially, a decision must be made regarding who will participate in the process.

Generation of Statements

The beginning of the concept mapping process is the generation of a set of statements, or ideas, about the research question. Ideally, the set of statements should represent the entire conceptual domain for the topic of interest. The present investigation utilized statements generated from a study by Ford (1993) entitled, Wives Adaptation to Husbands With Brain Injuries.

Following the removal of the redundant statements, the other statements were further reviewed by an interrater agreement process, and, were again reduced so there is a maximum of 80 statements. More than 100 statements has been found to be extremely difficult to sort into theme groups (Trochim, 1989).

Categorization of Statements

The initial step in identifying interrelationships between statements is to perform a card sorting procedure on the set of statements. Each statement is printed on a separate index card and the cards are arranged in random order. Next, a group of sorting participants is chosen. These may, or may not, be the same individuals who participated in the generation of the statements. In this study, the sorting task was done by a group of 25 independent sorters, other than the group that generated the statements. This is due to the difficulty in locating the original group that generated the statements. The group consisted 13 female and 12 male graduate student sorters, from the Faculties of Nursing, Medicine, Education, and Psychology. All participants were married and many had

children. A complete set of statements was given to each sorter with a cover letter and instructions to sort the statements into groups having a common theme or idea (see Appendix A). The cover letter was also used to inform the sorters about the purpose and nature of the research and that the return of the sorting task will be viewed as consent to participate in the research. The sorters were also told that they could discontinue their participation at any time. Trochim notes that some restrictions are placed on this procedure: "each statement can only be placed in one pile (i.e., an item cannot be placed into two piles simultaneously); all statements cannot be placed in one single pile; and, all statements cannot be put into their own pile, (although some items may be sorted by themselves)" (1989,p.5). Apart from these conditions, Trochim (1989) notes, sorters may pile the cards in any way that makes sense to them. The sorters were informed that the task would require approximately 45 minutes to complete. To ensure anonymity, the sorters were asked not to sign their names and were informed that only group results would be reported.

Statistical Analyses

Development of Themes

The sets of grouped statements collected from the sorting participants are then analyzed using multivariate statistical techniques which include multidimensional scaling (MDS) and a cluster analytic technique. These analyses will identify common underlying conceptual phenomenon or categories through the generation of point and cluster maps,

which emerge when item groupings determined by individual sorters are considered in combination (Trochim, 1989). In the present investigation, the representation of the statements in the form of concept maps is accomplished through the use of the *Concept System*, a computerized concept mapping program developed by Trochim (1989c).

Multidimensional Scaling

Multidimensional scaling (MDS) is primarily a quantitative model. It determines the interrelationships between individual items and can be used to develop a point map of items for conceptual purposes. The model does not categorize the items into groups and is therefore used in combination with some other subjective or statistical clustering method (Miller, Wiley, & Wolfe, 1986; Trochim, 1989).

Multidimensional scaling is the first statistical procedure carried out on the sort data in the concept mapping system described by Trochim (1989), which locates each statement as a separate point on a map (i.e., the point map). In concept mapping, the multidimensional scaling analysis, using a nonmetric two dimensional solution, places the set of points into a bivariate distribution which is suitable for plotting on an X-Y graph. A map of points is created which represents the set of statements that were based on a similarity matrix resulting from the sorting task. Statements that are closer to each other are more likely to have been sorted together more frequently, and therefore be related to the same concept. The opposite is true for statements which are found far apart. In summary, multidimensional scaling takes the table of similarities or distances and

repetitiously places points on a map so the original table is represented as accurately as possible.

Cluster Analysis

Trochim (1989) states that the second analysis in the concept mapping process, to represent the conceptual domain, is called a hierarchical cluster analysis (Anderberg, 1973; Everitt, 1980). This cluster analytic technique is applied to the X-Y multidimensional scaling coordinate values for each point. The purpose of this analysis is to group individual statements on the map into clusters of statements which presumably reflect similar concepts. Borgen and Barnett (1987) state that Ward's (1963) minimum variance technique is one of the most commonly used agglomerative hierarchical techniques, particularly in the behavioral sciences. Edelbrock (1979) found Ward's to be very effective in classifying psychopathology. Ward's method continues to rate as one of the most effective clustering analysis techniques for recovering underlying structure (Aldenderfer & Blashfield, 1984; Blashfield, 1984). Initially hierarchical cluster analysis gives as many cluster solutions as there are statements (Everitt, 1980). Ward's method is designed to minimize the variance with clusters at each stage of grouping. The method begins by considering each statement as its own cluster. The approach proceeds by merging those single objects or statements, or group of objects or statements that result in the least increase in the within-groups sums of squares (or error sums of squares). That is, at each stage of analysis the algorithm combines two clusters until, at

the end, all statements form one cluster. This approach tends to optimize within-cluster homogeneity at each stage of grouping. The method does not ensure optimum homogeneity of final clusters because once joined, objects are not separated at later stages of grouping. Trochim (1989) observed the utility of Ward's method in the concept mapping process stating that it "generally gave more sensible and interpretable solutions than other approaches" (p.8).

Development and Interpretation of Maps

Each group of statements, or themes, derived from the statistical analysis can be visually inspected and given a title, analogous to naming factors in a factor analysis, which seems to describe the contents of that group.

Trochim (1989) notes that a method to assist the researcher in determining the number of clusters and their labels is the computation of a "bridging index". The index is designed to help determine whether an item on a concept map is a good representation of the space in which it is located or whether it may be located where it is a compromise by the MDS algorithm. A higher value indicates that an item is more likely a "bridge" item having been sorted with statements in various locations on the map. The lower the bridging value the more likely the item was sorted primarily with statements that are close to it on the map. An average bridging index can also be computed for a cluster. In this case clusters with lower bridging values generally represent a more coherent set of

statements (Trochim, 1987b). In general, the lower the bridging, the more central the statement is for the meaning of the cluster.

The final result is a visual representation, or map, of the concepts developed in the analysis of the interrelationships among the sorted statements. Trochim (1989) notes that this map provides an easy to understand summary of the conceptualization process.

Utilization of Maps

The results of the concept mapping process can be used to plan or evaluate treatment programs and provide an understanding of the issues of interest from the participants perspective. Each category or grouping can be viewed as a measurement construct and can be used to provide direction for future research. Furthermore, the pictorial format of the actual map is likely to help people understand and retain the essential ideas more easily. In the latter regard it can be used for communication and educational purposes (Trochim, 1989).

Summary of Concept Mapping Statistical Analysis

Following the generation of statements through brainstorming or interviews, and structuring of statements through completion of the card-sort technique by participants, the results are combined across people. First, the results for each person are put into a square table or binary symmetric similarity matrix. Second, the individual sort matrices are added together to form a combined group similarity matrix. This final similarity matrix is considered the "relation structure" of the conceptual domain as it provides information about how the participants grouped the statements.

Multidimensional scaling techniques are then applied to the similarity matrix using a two-dimensional solution. This procedure locates each statement as a separate point on a map (i.e. the point map); statements which are closer to each other on this map are typically sorted together more frequently. These points are subjected to a hierarchical cluster analysis which produces a cluster map. Finally, each of the statements contained in the various clusters are read to describe or name the cluster.

CHAPTER 4: RESULTS

The purpose of this study was to conceptualize the process of adaptation of women following their husbands' brain injuries employing the Concept Mapping technique. An analysis of the qualitative data previously collected from Ford's (1993) study will be presented. The results of the investigation are presented in two sections. Section A describes the set of statements derived from the interrater agreement process for the first research question, "How has your husbands brain injury affected you?" Next the results of the multidimensional scaling and the cluster analysis will be discussed to explain the concept map for question one. This phase of the study attempted to identify themes within which these statements might fall. The results of Section A are discussed and related to previous research. Section B describes the set of statements derived from the interrater agreement process for the second research question, "How have you dealt with your husband's brain injury?" In addition, the concept map for question two is described and the results of Section B are discussed and related to findings in the literature.

Section A

Concept Map #1: How has your husband's brain injury affected you?

The first phase of the study in which the interrater agreement process was employed, resulted in the identification of a set of 77 statements for question one.

Once identified, the 77 statements made up the basis for a sorting task that was completed by 25 university graduate students. A sample of this size is appropriate for concept mapping. Kunkel (1993) contends that one can achieve very reliable cluster solutions with a sample size as low as fifteen. Too many sorters will result in redundancy of clusters. The sorters were asked to categorize statements by creating piles or groups that made sense to them. To develop the concept map, this sort data was analyzed using multidimensional scaling (MDS) and cluster analysis.

Multidimensional Scaling

The initial bit map of the 77 statements generated from question one is presented in Figure 1 (p. 55). The concept map of those same 77 statements is presented in Figure 2 (p.56). The 77 statements reduced from Ford's (1993) original statements through the interrater agreement process are presented as points on the map. The placement of points is derived from the MDS solution. The distance between the points represents the frequency with which the statements were sorted together by the volunteer university students. That is, points that are relatively close together represent items that are placed together in the participants' sorts more frequently than items represented by points more distant from each other. The MDS procedure resulted in a final stress value of .29 for a two-dimensional solution. The stress value is an index of the stability of an MDS solution and ranges from zero (perfectly stable) to one (perfectly unstable) and indicates the proportion of total variance that accounts for error. A cluster analytic technique is

performed on the points found on the MDS solution to assist in defining theme groupings.

Cluster Analysis

The second quantitative analysis in the concept mapping process is called a hierarchical cluster analysis. The purpose of this analysis is to group individual statements on the map into clusters which presumably reflect similar concepts.

Similar to other procedures, such as factor analysis, and latent partitioning analysis for categorical data, naming of the clusters is influenced by both statistical and conceptual considerations. Trochim (1989) notes that when using cluster analysis in this concept mapping technique, he begins by examining all cluster solutions from approximately 20 to 3 clusters. Furthermore, he states that the groupings obtained should be viewed as suggestive and that at times it is appropriate to visually adjust them. "We examine which statements were grouped together at a step and attempt to decide whether that grouping makes sense for the statements in the conceptualization" (Trochim, 1989, p.8). This is done in the context of maintaining the integrity of the multidimensional scaling results so that a clustering solution is obtained which does not allow any overlapping clusters (providing a true partitioning of space).

Trochim (1989) notes that a method to assist the researcher in determining the number of clusters and their labels is the computation of a "bridging index." The bridging index is calculated as a weighted average of the distances between the item and all the other items contained in the multidimensional solution found on the concept map.

The index is designed to help determine whether it may be located where it is a compromise by the MDS algorithm. The index is represented by a number between 1 and 0. A higher value indicates that an item is more likely a "bridge" item having been sorted with statements in various locations on the map. The lower the bridging value the more likely the item was sorted primarily with statements that are close to it on the map. An average bridging index can also be computed for a cluster. In this case clusters with lower bridging values generally represent a more coherent set of statements (Trochim, 1987b). In general, the lower the bridging, the more central the statement is for the meaning of the cluster.

The final cluster solution for the first concept map was determined by the author with the assistance of the Ph.D. psychologist who was part of the interrater process that identified the final 77 statements. In this analysis, consideration was given to the items in each cluster and to those items contributing most to the uniqueness of each cluster. Uniqueness was determined, in part, by the average bridging index for each cluster and the individual index for each statement. A final solution of ten clusters for question one was determined to be most appropriate based on the above criteria. To determine the appropriate number of clusters, cluster solutions ranging from 5 to 15 were examined for question one.

Concept Map 1: How has your husband's brain injury affected you?

The initial 15 cluster solution included clusters that appeared to be too fragmented. In many cases clusters contained few items and no clear themes were

together. Further reducing the number of clusters by one produced little change at each individual step. However, the reduction from 14 to 10 clusters served to collapse the clusters in all regions and gave what was felt to be the best interpretability.

Further reduction of the 10 cluster solution was deemed to be inappropriate. An analysis of nine clusters was observed to combine the clusters three (Responsibilities) and four (Resentment/Frustration). The third cluster was judged to be distinct with its items reflecting the importance of her new responsibilities. Reducing the solution to five clusters combined the concepts of (Positive Attitude to Self and Confidence/Independence); (Stress/Support with Resentment and Responsibilities); (Dependency Issues and Marital/Communication Difficulties and Verbal/Physical Abuse). Upon examination of this solution the clusters seemed to overgeneralize the contents and was not maintained. Any further reduction in the number of clusters analyzed (e.g. four, three or two) was judged to also produce an overgeneralization of the results. Appendix B includes the various cluster solutions examined and their bridging indexes. Items found within each cluster of the final ten cluster solution, together with their individual bridging indexes are found in Table 1.

TABLE 1

Cluster Items and Bridging Values for Concept Map of "How has your husband's brain injury affected you?"

Cluster/Items	Bridging Index
Cluster #1 - Positive Attitude to Self	
I realize how much I do care for him.	0.26
I've become a more caring person.	0.20
It has made us much closer as a family.	0.60
People were kind and stood behind us.	0.54
It has taken a lot of understanding and patience.	0.55
It's made me more aware of what's important in life.	0.07
I take pride in knowing I did the very best for someone I love.	0.12
I'm no longer shy and withdrawn.	0.07
It changed my attitude toward people with injuries.	0.18
Cluster Average	0.29
Cluster # 2 - Confidence/Independence	
I am more independent.	0.16
I became a survivor.	0.38

It made me go back to school.	0.75
I become much stronger emotionally.	0.00
It has given me more confidence in myself.	0.07
It has made me mature, and I do things I didn't think I could do.	0.13
I've come to know the Lord.	0.09
Cluster Average	0.23
Cluster #3 - Responsibilities	
I had to take over all responsibilities.	0.70
I had to take over all decisions.	0.70
My role changed, now everything is my responsibility.	0.70
Loss of income and I'm frustrated with finances.	0.54
I'm totally responsible for his care.	0.79
I have no one to discuss decisions with.	0.70
Cluster Average	0.69
Cluster #4 - Resentment/Frustration	
I haven't recovered yet.	0.53
I feel guilty for resenting and disliking him.	0.45
I've given up a lot-I feel bitter.	0.43
I'm not as carefree or easygoing.	0.67
I'm a lot more judgemental and have higher expectations.	0.66

Now I work because I have to.	0.75
I'm frustrated that I can't provide for the family.	0.70
Cluster Average	0.60
Cluster #5 - Stress/Support Issues	
Great increase in stress level.	0.41
His being home all the time is difficult.	0.62
Lack of support medically and from social services.	0.20
I was disappointed in the little support we received from the family.	0.41
I need coping skills and more support.	0.27
Lots of guilt for not being as good as one could.	0.33
Before this happened I was ready to update my education.	0.59
I'm mentally/emotionally drained.	0.32
I have had a lot of sleepless nights.	0.32
I cry a lot.	0.32
It's given me some really difficult times, worries.	0.42
Cluster Average	0.38
Cluster #6 - Loss Issues	
I became very protective of him.	0.78
It hurts to see him going through this.	0.51
There are some changes, irritating, but I live with them.	0.89

I miss him.	0.75
Lost social contact.	0.62
Our sex life is down the tubes.	0.78
There is no more love, everything is gone.	0.70
When one person in the house has a brain injury everyone has it.	0.77
Cluster Average	0.72
Cluster #7 - Family Adaptation	
It's been hard on the children.	0.13
The children had to grow up too fast.	0.13
He will side with the children rather than discipline them.	0.45
The kids missed out on their dad.	0.23
Family activities have declined and are at a minimum.	0.49
We've had to change our whole way of living.	0.91
I have to be the referee between him and the kids.	0.52
The family is careful not to upset him.	0.71
I couldn't leave the kids alone with him.	0.82
His health is poor, which affects the family.	0.74
Cluster Average	0.51

Cluster #8- Marital/Communication Difficulties	
He is not the same person, which has indirectly affected me.	0.56
He has mood swings, which causes stress for me.	0.57
It is very hard to get along with him.	0.62
He's had growing pains.	0.49
He complains that nobody talks to or listens to him.	0.58
He's too secretive with me.	0.22
He forgets everything.	0.50
He cannot hear too well-he cannot understand me.	0.62
Cluster Average	0.52
Cluster #9 - Dependency Issues	
He was unable to assume his role as a spouse.	0.92
He leaves things sit for months.	0.86
There are a lot of things he can't do physically.	0.75
My husband seems to depend on me for everything.	1.00
Cluster Average	0.88
Cluster #10 - Verbal/Physical Abuse	
He can't be caring.	0.35
He gets aggressive quickly.	0.17
He's mentally and verbally abusive.	0.40

He was very abusive both verbally and physically.	0.44
His functioning is quite variable.	0.53
Everything has to be his way.	0.47
My husband has talked about wanting out of the marriage.	0.95
Cluster Average	0.47

Cluster One - Positive Attitude to Self.

Cluster one was deemed to represent a concept that had a positive valence and included statements about positive attitude changes in the woman towards herself. Statements representing a more caring attitude included: "I realize how much I do care for him", "I've become a more caring person," and "I take pride in knowing I did the very best for someone I love." Another element in this cluster is the new awareness of an observable change in attitude and behavior, such as "It's changed my attitude toward people with injuries", "I'm no longer shy and withdrawn, "It's made me more aware of what's important in life", and "It has taken a lot of understanding and patience." The final element of this cluster is represented by two items identifying a realization that many positive things have happened as a result of the injury: "People were kind and stood behind us" and "It has made us much closer as a family." In terms of the bridging index, this cluster attained the second lowest average bridging values.

Cluster Two - Confidence/Independence

The second cluster, which is adjacent to the first, also includes statements that have a positive valence, and represent positive changes in lifestyle (e.g., "It has made me mature, and I do things I didn't think I could do"). In addition, most of the items in this cluster represent the development of an inner confidence and independence: "I am more independent", "It has given me more confidence in myself." Two of the items indicate increased emotional strength: "I have become much stronger emotionally", and "I became a survivor." In terms of the bridging index, this cluster attained the lowest average bridging values. This can be interpreted as the more likely the items in this cluster were sorted primarily with statements that are close to it on the map.

Cluster Three - Responsibilities

The third cluster is at the lower right side of the map. It is grouped near clusters that share a negative theme. This cluster contains items that describe an overall increase in the woman's responsibilities and decision making, and the frustration with a change in roles: "My role changed, now everything is my responsibility", and "I have no one to discuss decisions with." This cluster attained the third highest average bridging values, meaning that some of the items could have been sorted with nearby clusters.

Cluster Four - Resentment/Frustration

This fourth cluster is grouped on the central right side of the map and represents a negative theme. This cluster contains items that describe negative feelings within the

woman, since the injury. Some of the statements describe guilt feelings such as "I feel guilty for resenting and disliking him", and general frustration; "I'm frustrated that I can't provide for the family." Two of the items describe a built up of resentment such as, "I've given up a lot-I feel bitter", and "Now I work because I have to."

Cluster Five - Stress/Support Issues

The fifth cluster is grouped next to clusters three and four on the map, and much like the previous two clusters, indicates a negative valence. Two elements emerge in this cluster.

The first element is the overall increase in stress level and symptoms of stress such as, "Great increase in stress level", "I've had a lot of sleepless nights", and "I cry a lot." The second element involves support issues and the feeling of a lack of support from many sources. (e.g. "Lack of support medically and from social services", and "I was disappointed in the little support we received." This cluster has the third lowest bridging value indicating a high degree of similarity in the frequency with which these items were rated together. Clusters three, four and five are very close together on the map, which could be interpreted as concepts that are closely related in some way.

Cluster Six - Loss Issues

Cluster six appears to contain statements describing loss issues within herself, within the relationship and socially. The first element relates to feelings of sadness and loss within herself (e.g. "It hurts to see him going through this", and "I miss him"). The second element relates to a breakdown in their marital relationship, and the feelings of loss which accompany it. (e.g. "There is no more love, everything is gone", and "Our sex life is

down the tubes"). The third element in this cluster relates to a decrease in socializing with others (e.g. Lost social contact).

Cluster Seven - Family Adaptation

Cluster seven contains statements that describe the impact of her husband's injury on the family. One theme that emerges is how the injury has negatively affected the children: "It's been hard on the children", "The children had to grow up too fast", and "The kids missed out on their dad." The second theme relates to a decrease in family activities: "Family activities have declined and are at a minimum", and "We've had to change our whole way of living." The third element describes how the family relates to the injured spouse: "The family is careful not to upset him", and "I had to be the referee between him and the kids."

Cluster Eight - Marital/Communication Difficulties

The eighth cluster found in the lower left region of the map reflects the communication difficulties in the marriage due to a change in the husbands personality (e.g. "He is not the same person, which has indirectly affected me", and "He's too secretive with me.") In addition, a decrease in his cognitive functioning exacerbates this problem: "He forgets everything", and "He cannot hear too well-he cannot understand me." The other item in this cluster describes her reaction to these personality and cognitive changes: "It is very hard to get along with him."

Cluster Nine - Dependency Issues

Cluster nine appears to contain statements that reflect the husbands physical dependency:

"There are a lot of things he can't do physically." Another element in this cluster describes how the husband has become very dependent on his spouse: "He was unable to assume his role as a spouse", and "My husband seems to depend on me for everything." This cluster has the highest bridging value indicating that these items were more likely "bridge" items having been sorted with statements in various locations on the map.

Cluster Ten - Verbal/Physical Abuse

Cluster ten represents a theme of abuse, both verbal and physical in the relationship. (e.g. "He can't be caring", and "He's mentally and verbally abusive"). Another element in this cluster describes the husbands resistance to see the family's point of view, "Everything has to be his way." The final element describes the unpredictable nature of his behavior: "His functioning is quite variable", and "He gets aggressive quickly."



Figure 1: Initial point bi map of the 77 statements generated from question One

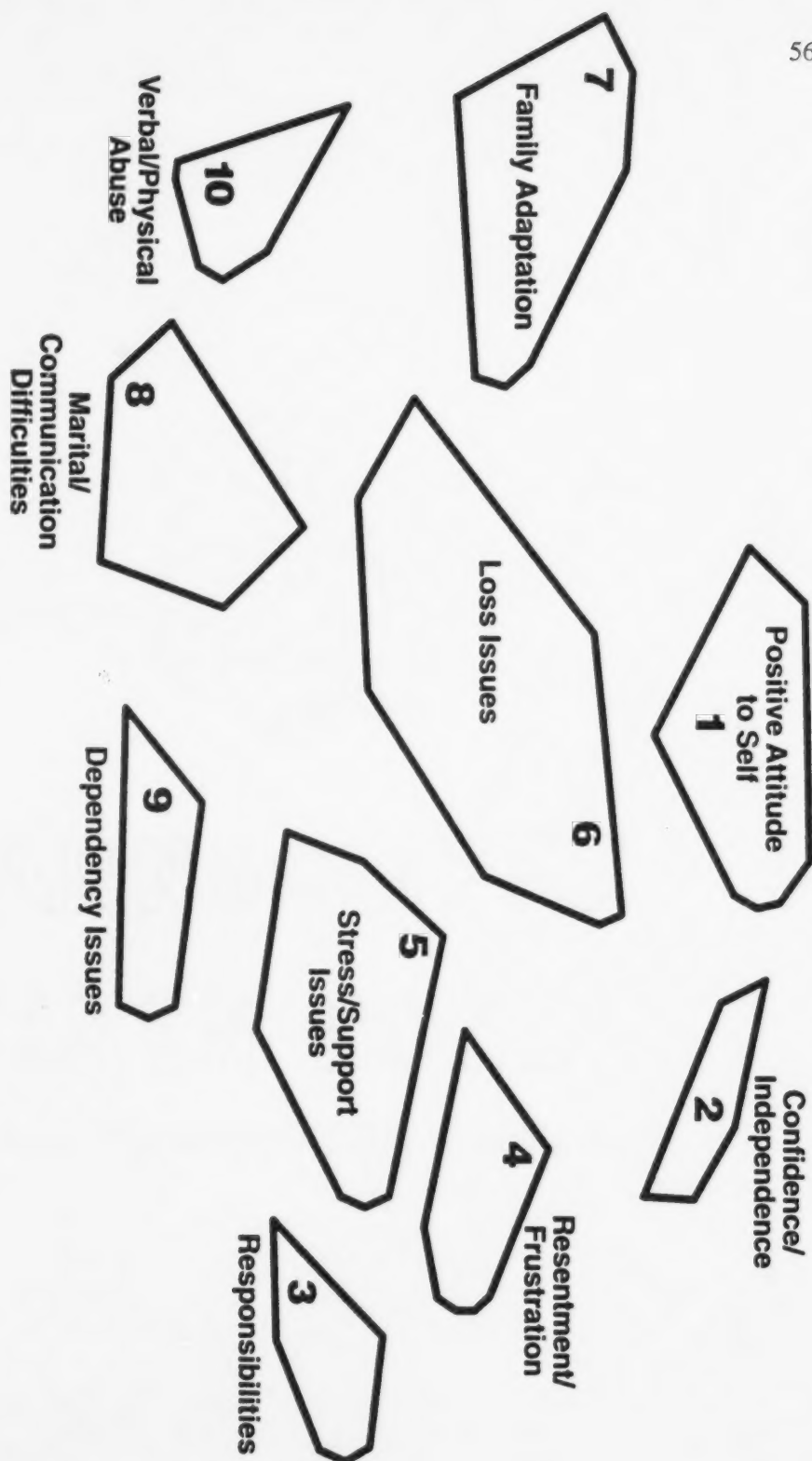


Figure 2: Concept map of 77 statements for question one:
How has your husband's brain injury affected you?

Discussion

Section A

In relation to the first open-ended question "Please list the ways in which your husband's brain injury has affected you" the following general themes emerged from the concept map (see Table 2). The first general theme referred to Positive changes within the women with regards to attitude towards herself and her marriage. This experience made them more appreciative of their husbands. The second theme referred changes in levels of confidence and independence. In addition, the women reported feeling emotionally stronger as a result of the injury. The third theme referred to an increase in responsibilities. Additional responsibilities were given to these women, such as finances, household and car repairs, and yardwork. The fourth theme had to do with an increase in resentment and frustration experienced by the women. It relates to the feelings of guilt of not providing for the family as well as they could and the bitterness of having to do everything. The fifth theme referred to an increase in stress for the women due to increased responsibilities, worries, and the absence of support. This lack of support came from family, health care professionals, social services, and the government. A sixth general theme emerged relating to loss issues. It referred to a negative change in their lifestyle relating to social life, sexuality, and the emotional loss regarding the change in his personality. The seventh theme referred to the Family's Adaptation to the brain injury. It contained maladaptive items that described how the women and children interacted

with their injured father, such as "The family is careful not to upset him", and "I have to be the referee between him and the kids." Some women felt that their children had to "grow up" more quickly. The eighth theme related to Marital/Communication difficulties as they relate to personality and emotional changes within the husband. This change produced an overall increase in stress for the women. The ninth theme relates to dependency issues. A number of the items in this cluster described the husbands as not assuming their roles as husbands and fathers. Other items indicated that the husbands had regressed to a childlike state of dependency. Examples of statements which best illustrate the negative aspects of this theme are: He was unable to assume his role as a spouse. Other negative changes relate to his decrease in physical functioning making him more dependent: There are a lot of things he can't do physically. The tenth theme related to Verbal and Physical Abuse issues.

Relationship to Previous Research

The purpose of this study was to investigate the process of adaptation of women following their husbands's brain injuries, employing the Concept Mapping Method. This was done by analyzing the two open-ended questions from Ford's (1993) study. Question one: How has your husband's brain injury affected you? resulted in a concept map with 10 cluster themes. The 10 clusters or themes included Positive Attitude to Self, Confidence/Independence, Responsibilities, Resentment/Frustration, Stress/Support Issues, Loss Issues, Family Adaptation, Marital/Communication Difficulties, Dependency

Issues, and Verbal/Physical Abuse. In the following section, the results of the study are discussed and placed within the context of the literature presented. Some elements of the concept map themes are consistent with the existing spousal adaptation to traumatic brain injury literature.

The overall themes which emerged from the first question appear to share some similarities with Ford's (1993) investigation. Several themes and subthemes were derived from the first open-ended question. These include (1) changes in the husbands; (2) Changes within and for the women, such as positive changes regarding personality qualities and attributes, an increase in stress, and an increase in negative feelings; (3) Changes in relationships such as, marital, with the children, within the family; (4) Changes in lifestyle (positive and negative) and (5) Feelings of support or feelings of a lack of support.

Positive Attitude to Self

Some of the women describe positive changes in terms of themselves (personality qualities and attributes) and in terms of relationships within the family. These women describe a variety of changes including feeling more caring, no longer shy and withdrawn, and an awareness of what's important in life, in relation to confronting the challenges of the effects of their husbands' brain injuries. This theme is consistent with the literature on maintaining a positive attitude as a coping strategy (Karpman, Wolfe, & Vargo, 1985). The experience appeared to make them more appreciative of their husbands.

Confidence/Independence

These women describe a variety of changes including feeling stronger, more competent, more assertive, and more independent in relation to dealing with the effects of their husbands' brain injuries. This theme corresponds with themes of internal strength in the coping literature (Karpman, Wolfe, & Vargo, 1985). Willer et al. (1991) report on the problems and coping strategies of individuals with traumatic brain injuries and their spouses. One of the coping strategies listed in their study was becoming assertive in dealing with daily obstacles they encountered.

Responsibilities

This theme of responsibilities is consistent with the stress literature (McCubbin, & McCubbin, 1991). They describe families as experiencing a "pile up of demands", as is the case when a spouse has to assume additional responsibilities as a result of her husbands' head injury. Moreover, the additional responsibility of the wife returning to work in order to provide financial support for the family may cause additional stress for the woman. Zeigler (1989) investigated the importance of mutual support for spouses of head injury survivors. One of the topics discussed included role changes with significantly increased responsibility.

Resentment/Frustration

This theme is consistent with the psychosocial burden literature (Allen et al., 1994; Jacobs, 1987; McKinlay et al., 1981, Oddy et al., 1978). One source of burden is the family's concern for the future care of the individual with traumatic brain injury

(Oddy et al., 1978). In a related study, long term financial issues were a concern for all caretakers. Many women describe significant role changes in terms of their responsibilities in the home and in their marital relationships. The changes in lifestyle relate primarily to finances, social life, and recreation and tend to have a negative effect on the women.

Stress/Support Issues

This theme is consistent with those researchers who have described the negative effects for the wives of those with brain injuries (Brooks et al., 1986; Brooks & McKinlay, 1983; Kreutzer, Gervasio, & Camplair, 1994; Lezak, 1988; Liss & Willer, 1990; Livingston et al., 1985; McKinlay et al., 1981; Rosenbaum, & Najenson, 1976; Thomsen, 1987; Willer et al., 1991).

Rosenbaum and Najenson (1976) demonstrated that greater stress was experienced by the wives of the men with brain injuries. The spouses of men with brain injuries reported decreased leisure time, fewer contacts with friends, and greater disruption in their marital relationships.

The element of lack of support is consistent with the social support literature (Vargo, 1983; George & Gwyther, 1986; Monahan & Hooker, 1995; Scott et al. 1986). Vargo (1983) reported that the presence of adequate, functional support systems was the single most important factor in the way in which these women reacted. When these support systems were absent or functioning poorly, the effect was negative. Scott et al.

(1986) report that socio-emotional support from family members is positively associated with more effective coping styles in Alzheimer's caregivers.

Women describe a lack of support from extended family members, professionals, social services, and the government. The low levels of support the women report from professionals, community groups, is consistent with Jacobs (1987) who suggests that there is a lack of support from long-term rehabilitation support services. This finding is also consistent with that of Unger and Powell (1980) who suggest that when families are in need of help they do not seek initial aid from formal organizations, even if the organization is designed to serve the individual's presenting problem.

Loss Issues

This theme of loss is consistent with the marital adjustment literature (Earnes & Wood, 1989; Lezak, 1988). Lezak (1988) reports that it is difficult for spouse to work through the feelings surrounding mourning and loss, because society does not recognize the feelings of loss when a loved one's personality changes. Lezak (1988) also suggests that when a partner in a stable marriage sustains a severe head injury, their spouse loses a close companion, and one of their major sources of emotional support and affection. In addition, Liss and Willer (1990) demonstrate that spouses's reactions to traumatic brain injuries include feelings of anxiety, isolation, and loss.

Family Adaptation

McCubbin and McCubbin (1991) describe family adaptation as a concept which describes a continuum of outcomes that reflect efforts to achieve a balance at two levels

of functioning (individual to family and family to community). This theme falls at the negative end of the continuum, family maladaptation, which is characterized by a deterioration in the quality of family relationships, and the loss of family independence and autonomy.

Marital/Communication Difficulties

In terms of Marital/Communication Difficulties, the women describe numerous negative effects of their husbands' brain injuries on their marital relationships. These results support various researchers who describe the negative effects of brain injuries on marital relationships (Eames & Wood, 1989; Jacobs, 1989a; Jennett, 1990; Lezak, 1988; Rosenbaum & Najenson, 1976; Thomsen, 1989). This theme illustrates the distress felt by these women as a result of the personality changes in their husbands and the role changes that occur for themselves. These findings support those of Willer et al. (1989) and Lezak (1988) who found that changes in the personalities of the husbands and changes in the degree of companionship and emotional support previously offered by husbands are particularly distressing for these women. This finding is also consistent with that of Eames and Wood (1989) who found that sudden role changes following a brain injury are a major source of stress in the marriage.

In terms of the qualitative analyses one of the major themes to emerge is "changes in the husband". These changes are mostly considered to be negative and include changes in personality, emotional expression, cognition, and physical functioning. In addition, to

the stress experienced by the women in relation to changes in their husbands, other related burdens include financial strain and role changes for the women. (Ford, 1993).

Dependency Issues

This theme relates to the women expressing concern about their need to take over the parenting roles of their husbands and the childish and often jealous behavior expressed by their husbands in relation to other children. This finding is consistent with that of Willer et al. (1991) who also found that women express concerns regarding the effects on their children of having fathers with brain injuries.

Verbal/Physical Abuse

The theme of Verbal/Physical Abuse appears to be consistent with the growing literature on the relationships between Aggression and Head injuries (Rosenbaum, & Hoge, 1989; Rosenbaum, Hoge, Adelman, Warnken, Fletcher & Kane, 1994; Warnken, Rosenbaum, Fletcher, Hoge & Adelman, 1994). A recent study suggests that head injury may be a potentially useful factor in explaining some types of aggressive behavior. The authors have been able to demonstrate an association between head injury and marital aggression, and they identify several risk factors for relationship aggression and marital discord that may be sequelae of a significant head injury (Warnken, Rosenbaum, Fletcher, Hoge & Adelman, 1994).

Section B

Concept Map # 2: How have you dealt with your husband's brain injury?

The second phase of the study in which the interrater agreement process was employed, resulted in the identification of a set of 80 statements for question two.

Once identified, the 80 statements made up the basis for a sorting task that was completed by 25 university students. The sorters were asked to categorize statements by creating piles or groups that made sense to them. To develop the concept map, this sort data was analyzed using multidimensional scaling (MDS) and cluster analysis.

Multidimensional Scaling

The final stress value for the MDS solution was .22, and is even more acceptable than the MDS solution for concept map one. The initial bit map of the 80 statements generated from question two is presented in Figure 3 (p.78). The concept map of those same 80 statements is presented in Figure 4 (p.79). The 80 statements reduced from Ford's (1993) original statements through the interrater agreement process are presented as points on the map.

The final cluster solution for the first concept map was determined by the author with the assistance of the PhD psychologist who was part of the interrater process that identified the final 80 statements. In this analysis, consideration was given to the items in each cluster and to those items contributing most to the uniqueness of each cluster. Uniqueness was determined, in part, by the average bridging index for each cluster and the individual index for each statement. A final solution of seven clusters for question two was determined to be most appropriate based on the above criteria. To determine the

appropriate number of clusters, cluster solutions ranging from 6 to 16 were examined for question two.

The initial 16 cluster solution included clusters that appeared to be too fragmented. In many cases clusters contained few items and no clear themes were emerging. Next, solutions were examined by reducing the number of clusters by two. Moving from 16 to 14 clusters had a slight effect by only bringing clusters 1 and 2 together, and 8 and 9 together. Further reducing the number of clusters by two produced little change at each individual step. An eight cluster solution was deemed inappropriate, as it separated clusters 4 and 5, which appear to share a common theme of Counselling/Support Groups. However, the reduction from 16 to 7 clusters served to collapse the clusters in all regions and gave the best interpretability.

Further reduction of the 7 cluster solution was deemed to be inappropriate. An analysis of six clusters was observed to combine the clusters two (Time for Self) and three (Patience/Open Mind). The second cluster was judged to be distinct with its items reflecting the importance time for herself as a method of coping. Upon examination of this solution the clusters seemed to overgeneralize the contents and was not maintained. Any further reduction in the number of clusters analyzed (e.g. five, four or three) was judged to also produce an overgeneralization of the results. Appendix C includes the various cluster solutions examined and their bridging indexes. Items found within each cluster of the final seven cluster solution, together with their individual bridging indexes are found in Table 2.

Table 2:

Cluster Items and Bridging Values for Concept Map of "How have you dealt with your husband's brain injury?"

Cluster/Items	Bridging Index
Cluster #1 - Coping via distractions	
I do a lot of reading.	0.28
I keep a journal.	0.22
I've become involved in volunteer work.	0.24
I went back to school, took upgrading.	0.49
Sometimes I escape by going to sleep.	0.08
I use medications.	0.05
I go to work; it's my escape.	0.26
I walk a lot.	0.07
Sometimes I go for a drive to get peace of mind.	0.00
I keep busy and find things to do: ie. crafts, curling.	0.03
I've done a lot of talking to myself-to cope.	0.20
I cried a lot.	0.26

I try not to get terribly depressed.	0.26
I try to keep problems to myself.	0.34
I go on a little shopping spree-it's just a little lift.	0.00
Cluster Average	0.19
Cluster # 2 - Time for Self	
I've learned to live with it.	0.41
I try to stay calm.	0.32
Knowing how fast time goes by.	0.80
I take one day at a time, and I give myself time.	0.27
Sometimes I just tune him out.	0.28
My time is mine.	0.22
A lot of times I tend to forget about it.	0.33
Cluster Average	0.38
Cluster #3 - Patience/Open Mind	
I look for the good that happened that day.	0.54
I have a lot of patience.	0.49
I've kept an open mind.	0.48
I try not to be bitter or selfish.	0.62
I had to overcome my belief that I could "do it all".	0.63
I find a solution and deal with it.	0.60

I had to change my standards.	0.41
I've learned to adjust myself to his moods.	0.52
I had to learn to put my foot down, to be assertive.	0.63
I have adjusted time schedules, and dropped activities in order to accommodate the changes.	0.95
Cluster Average	0.59
Cluster #4 - Counselling/Support Groups	
I attend counselling.	0.71
Moving to a smaller town was helpful.	1.00
I listen to a particular family program.	0.83
I hope that there would be help.	0.55
I got funding.	0.76
I went to a NABIS meeting.	0.41
We're very aware of support groups but don't use them.	0.88
I talked to our family doctor about it.	0.24
Career Connectors in our small town have given me some help.	0.25
I've talked to doctors-family physician, psychologist, and specialist.	0.08
I began a brain injury support group.	0.63
Cluster Average	0.58

Cluster #5 - Family/Friends Support	
I have contact with friends.	0.54
I've taken him to various doctors and professionals.	0.63
My husband and I sought marital and family counselling.	0.41
Initially I had homecare, but it's an intrusion.	0.45
My husband's company has been ace.	0.40
Our church and my faith has been a big support.	0.19
We moved back to the city to facilitate my employment and better medical attention for my husband.	0.69
Learning about it from the library and from professionals was helpful.	0.23
My husband attends counselling.	0.26
We have a good family doctor who listened and gave advice.	0.13
I've had support from family.	0.38
Everyone around me was supportive.	0.32
The kids were and are a tremendous support for me.	0.53
Cluster Average	0.40
Cluster #6 - Family Cohesiveness	
It helped me to see the kids handle it so well.	0.63
I accept they (the family) can't do everything.	0.69

As a family we're extremely open about talking and laughing about it (the brain injury).	0.23
Teasing and joking about it works well for us as a family.	0.24
My husband and I have a real sense of family.	0.37
I would never consider leaving him.	0.60
We talk about it-we have good communication.	0.50
We try to do things socially together- like movies.	0.41
We tried to keep as normal as life as possible.	0.58
I love my husband and its important that we stay together as a family.	0.40
Sometimes we've stayed away from people in order to have time alone.	0.87
Cluster Average	0.50
Cluster #7 - Supportive/Nurturing Role	
I try to understand and keep accepting the way he is.	0.63
I'm grateful for every little improvement.	0.83
I had some problems to get him to go out and communicate with others.	0.65
I overlooked many things-not his fault.	0.59
I need to wean him (from me) he's very demanding.	0.92

I don't want to put negative feelings against my husband with my family.	0.97
I was very supportive of him.	0.66
I think it takes more work to work things out.	0.78
I spent a lot of time at the hospital with my husband.	0.52
I deal with him as I would my teenage sons.	0.78
I can calm him down.	0.49
I had to simplify a lot of things for him-to explain routines.	0.44
I try to help him remember things and keep his brain active.	0.45
Cluster Average	0.67

Cluster One - Coping via Distractions

Cluster one was deemed to represent a concept that had an a somewhat negative element of coping with her husband's brain injury via distractions. This cluster is located in the lower right corner of the map. Statements representing elements of escapism included: "Sometimes I escape by going to sleep", and "I go to work, it's my escape." Another element in this cluster indicated the tendency to leave the house for a short period of time: "Sometimes I go for a drive to get peace of mind", and "I go on a little shopping spree-it's just a little lift, and "I walk a lot." Some healthy aspects of this cluster include "I keep a journal," and "I've done a lot of talking to myself to cope," and "I cried a lot." Another

element revealed educational interests such as: "I went back to school, took upgrading," and "I do a lot of reading." One item in this cluster represented the need to use medications as a form of coping; "I use medications." The final element of this cluster is represented by two items identifying the need to appear happy and to keep problems to herself; "I try not to get terribly depressed," and "I try to keep problems to myself." In terms of the bridging index, this cluster attained the lowest average bridging values. This can be interpreted as the more likely the items in this cluster were sorted primarily with statements that are close to it on the map.

Cluster Two - Time for Self

The second cluster, which is adjacent to the first, also includes statements that represent the need for the woman to take time for herself. One element describes how the woman uses time to cope. For example "I take one day at a time, and I give myself time," and "My time is mine". Another element which is represented by two items describes her temporary ability to forget about it; "A lot of times I tend to forget about it," and "Sometimes I just tune him out." The final element represents her ability to use the passage of time as a coping mechanism; "Knowing how fast time goes by," and "I've learned to live with it." In terms of the bridging index, this cluster attained the second lowest average bridging values.

Cluster Three - Patience/Open Mind

The third cluster is in the center of the map. This cluster contains items that describe her ability to remain patient and flexible with her husband. For example, "I have a lot of

patience", "I had to change my standards" and "I've learned to adjust myself to his moods." Another element revealed her ability to keep an open mind to prevent from becoming bitter. "I've kept an open mind," and "I try not to be bitter or selfish." Another element represented her ability to be patient with herself in making decisions; "I had to overcome my belief that I could do it all," and "I had to learn to put my foot down, to be assertive." This cluster attained the second highest average bridging values, meaning that some of the items could have been sorted with nearby clusters. One element attained an extremely high bridging value-"I have adjusted time schedules and dropped activities." Therefore, this item is not central to this cluster, it could easily belong to Cluster 7.

Cluster Four - Counselling/Support Groups

This fourth cluster is grouped on the top right side of the map and represents a positive theme. This cluster contains items that describe the use of Counselling and Support groups to effectively cope with the brain injury. One element which is represented by three items describes the woman's use of counselling and support groups: "I attend counselling," "I went to a NABIS meeting," and "I began a brain injury support group." Two of the items describe the supportive aspects of living in a small town; "Moving to a smaller town was helpful," and "Career Connectors in our small town have given me some support." Another element represents the support provided by the medical profession: "I talked to our family doctor about it," and "I've talked to doctors-family physician, psychologist." In addition, there was an element of financial support: "I got funding." The final element represents the woman's decision to not use support groups

but rather obtain support from within the home. This is evident in items such as "We're very aware of support groups but don't use them," and "I listen to a particular family program."

Cluster Five - Family/Friends Support

The fifth cluster is grouped near the top center of the map. It is very close to cluster 4 on the map, and indicates similar themes. Two elements emerge in this cluster. The first element describes the support provided by friends in the community: "Everyone around me was supportive." One of the items describes her husband's company as being extremely helpful: "My husband's company has been ace," and another item identifies the support provided by the church and by personal faith: "Our church and my faith has been a big support." Another element describes community support from mental health and medical professionals: "I've taken him to various doctors and professionals," "My husband and I sought marital counselling" and "We have a doctor who listened and gave advice." The previous element appears to be similar to items in cluster 4- Counselling/Support Groups. It may be necessary to consider these two groups as sharing a common theme of Support from others. Another element involves support from family: "I've had support from family," and "The kids were and are a tremendous support for me." A final element represents employment as a form of support: "We moved back to the city to facilitate my employment." However, this item received a relatively high bridging value compared to the other items in this cluster. This means that it could have easily been grouped in another cluster such as cluster 4. Nevertheless, this cluster has the

third lowest bridging value indicating a high degree of similarity in the frequency with which these items were rated together. As previously mentioned, Clusters four and five are very close together on the map, which could be interpreted as concepts that are closely related in some way. A common theme which emerges is Support from Others.

Cluster Six - Family Cohesiveness

Cluster six appears to contain statements describing the families ability to remain intact and cope with the brain injury as a family. Cluster 6 is located at the top left of the map. The first element relates to the family's openness and sense of humour since the accident: "As a family we're extremely open about talking and laughing about it (the brain injury)," "Teasing and joking about it works well for us as a family," and "We talk about it-we have good communication." Another element describes the woman's new found sense of family: "My husband and I have a real sense of family," "I would never consider leaving him", and "We try to do things socially together-like movies." The final element contains one item, relating to the woman's perception of how the children have dealt with her husband's brain injury: "It helped me to see the kids handle it so well."

Cluster Seven - Supportive/Nurturing Role

Cluster seven contains two elements that describe the woman's role as a supportive caregiver. The first element describes the amount of support she provided for him: "I spent a lot of time at the hospital with my husband," "I was very supportive of him". Another element describes the type of support she gave to him: "I had to simplify a lot of things for him-to explain routines", and "I try to help him remember things and keep his

brain active." Another element describes a parental role emerging such as: "I deal with him as I would my teenage sons", "I need to wean him (from me)-he's very demanding," and "I can calm him down." A final element reveals a general supportive attitude towards her husband; "I try to understand and keep accepting the way he is", and "I'm grateful for every little improvement." This cluster attained the highest average bridging value, meaning that quite a few of the items could easily belong to clusters three or six.



Figure 3: Initial point bit map of the 80 statements generated from question two.

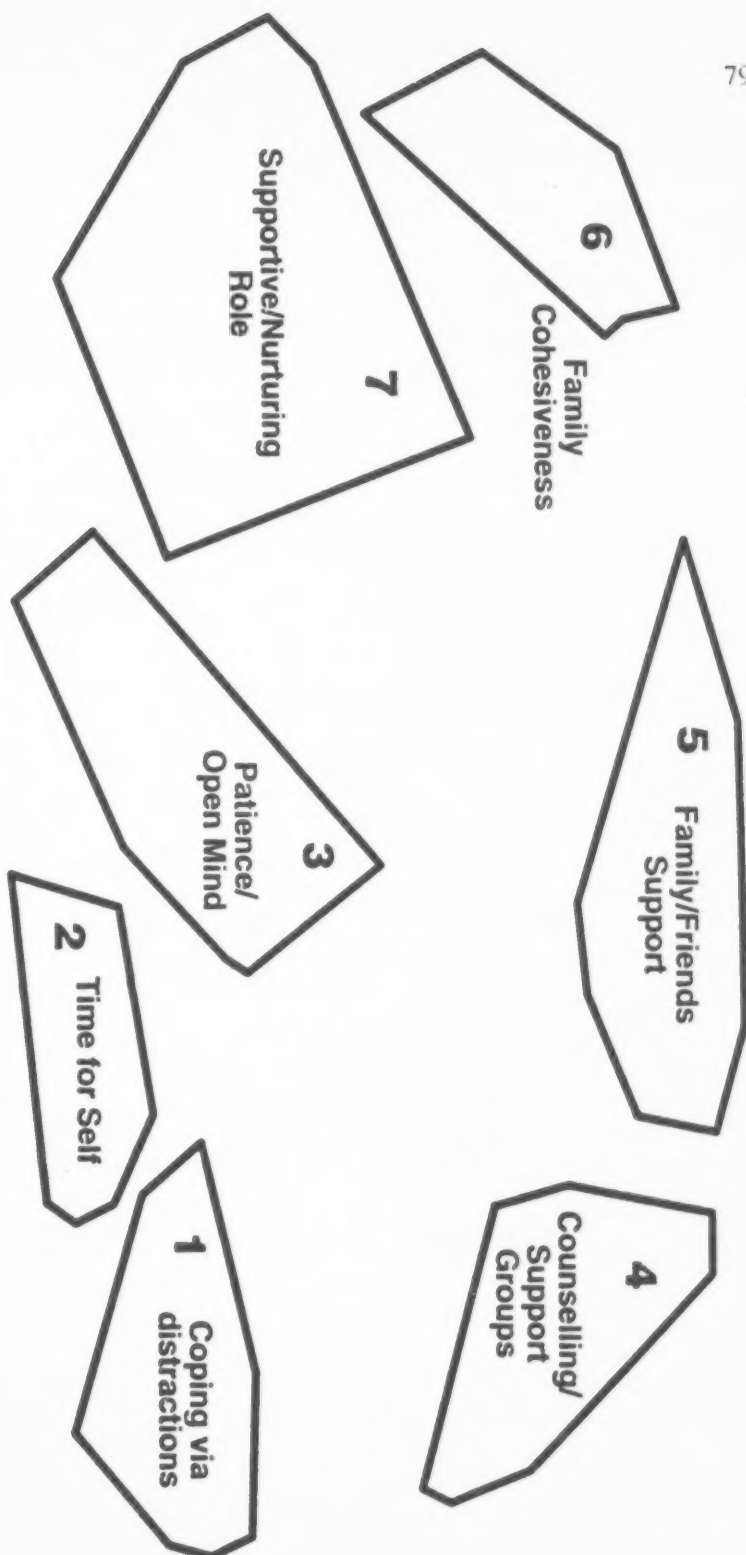


Figure 4: Concept map of 80 statements for question two:
How have you dealt with your husband's brain injury?

Discussion

In relation to the second open-ended question "Please list the ways in which you have dealt with your husband's brain injury", the following general themes were derived from the concept mapping method (see Table 2). As a first theme, the women described various activities which helped them deal with their husbands' brain injuries. Many women described their work as a form of escape from the stresses and conflicts at home. The women pursued a wide variety of leisure and recreational activities to help them deal with the consequences of their husbands' brain injuries. Some of these included solitary pursuits such as crafts or reading. The second theme which emerged relates to the need to take time out for self-care. A few of the statements reveal a behavior of ignoring the husband as a coping mechanism, such as "Sometimes I just tune him out". The third theme of greater patience/open mind represents the various actions, thoughts, attitudes, and outlooks which helped the women deal with their husbands' brain injuries. Themes four and five described various sources of support which helped them to deal with their husbands' brain injuries. One source of support was social support which included both immediate and extended family and friends. Other statements revealed that the children provided a strong source of support for these women. Several women attended individual, marital, or family counselling as a means of dealing with their husbands' brain injuries. Other types of support occurred through brain injury organizations, hospitals, or private organizations. Several women received support in terms of financial resources.

The sixth theme which emerged represents the family's ability to remain healthy and intact since the brain injury. An important aspect of this theme was the strong sense of commitment many of these women had to the relationships with their husbands. The seventh theme relates to the spouses role as supporter and nurturer. Statements within this theme indicated that the women just accepted the additional work and strain, while remaining very supportive.

Relationship to previous research

The concept mapping themes which emerged from the second question appears to reveal some similarities with Ford's (1993) study on Wives Adaptation to Husband's with Brain Injuries.

In her study, the themes to emerge in relation to the ways in which the women dealt with their husbands' brain injuries include (a) activities; (b) support; (c) behaviors, thoughts, attitudes, and outlooks; and (d) faith (Ford, 1993). The only theme that did not emerge in the present study is a theme which represents faith or organized religion as a means of dealing with the effects of their husbands' brain injuries.

Coping via distractions

This theme occurs throughout the coping literature (Klonoff & Prigatano, 1987; Willer et al., 1991). Klonoff and Prigatano (1987) conceptualize coping styles along two broad dimensions (a) functional/expected and (b) dysfunctional. Some of the items within this theme could fall within the dysfunctional end of the continuum. For example, "I try to keep problems to myself", and "Sometimes I escape by going to sleep." However,

Willer et al. (1991) suggest getting away from family pressures is an effective coping strategy.

Time for Self

This theme is consistent with the coping literature (Willer et al., 1991). Willer et al. (1991) suggest that one of the coping strategies employed by women whose husbands had suffered brain injuries is taking time for themselves. Moreover, taking time for themselves is consistent with McCubbin and McCubbin's (1991) model of family adjustment and adaptation. They emphasize two major sets of capabilities (a) resources and strengths, which are what the family has and (b) coping behaviors and strategies, which are what the family does. Taking time for themselves would fall into the latter category.

Patience/Open Mind

This theme is consistent with the literature on personal resources (McCubbin & McCubbin, 1991). In their model of family adaptation, McCubbin & McCubbin (1991) consider there to be adaptive resources within the individual family members. The first source of resources are personal resources and relates to the theme of Patience/Open Mind. These include such things as personality traits; physical and emotional health; a sense of mastery; and self-esteem. In addition, Vargo (1983) suggests six factors as being of primary importance to the satisfactory process of adaptation. One of the factors is hope, which relates to some of the elements within this theme.

Counselling/Support Groups

This theme is consistent with the counselling and support groups literature as a method of coping with head injury (Karpman et al., 1985; McCubbin & McCubbin, 1991; Willer et al., 1991; Vargo, 1983; Zeigler, 1989). Zeigler (1989) investigated the importance of mutual support for spouses of head injury survivors and suggested the use of mutual support or spouse support groups as a coping tool. These findings are consistent with those of Karpman et al. (1985) and Willer et al. (1991) who describe similar strategies used by women to cope with the effects of their husbands' brain injuries.

Family/Friends Support

This theme is consistent with the numerous studies in the literature on caring for individuals with Alzheimer's disease emphasizing the importance of social support (Monahan & Hooker, 1995; Aronson et al., 1984; Cantor, 1983; Gilhooley, 1984; Quayhagen & Quayhagen, 1988; Scott et al., 1986; Sistler, 1989). Scott et al., (1986) report that socio-emotional support from family members is positively associated with more effective coping styles in Alzheimer's caregivers.

Women describe receiving both emotional support and practical assistance (with house and yard work) from family and friends. The women emphasized the children as a source of support. This finding is consistent with that of Vargo (1983) who, in a study of the adaptation to disability by the wives of men with spinal cord injuries, found that one important factor to a satisfactory outcome is children. In addition, she concluded that the

presence of adequate, functional support systems was the single most important factor in the way in which these women reacted.

Family Cohesiveness

This theme is consistent with literature on family system resources (Karpman, Wolfe, and Vargo, 1985; Maitz, 1990; McCubbin & McCubbin, 1991; Vargo, 1983). McCubbin & McCubbin (1991), describe family system resources as characteristics of the family system itself, making the family less vulnerable to stress and/or better able to withstand the impact of stressors and crises. These resources include cohesion, adaptability, family organization and communication skills. Another study indicated that the loss of family cohesion in the head injury couples is crucial in that it compromises the family's ability to respond to crises (Maitz, 1990). Karpman, Wolfe, and Vargo (1985) investigated the process of psychological adjustment of the parents of 10 adults who had sustained brain injuries. They identified 12 coping strategies, one of which is cohesion and cooperation within the family. Vargo (1983) suggests a commitment to the marital relationship is of primary importance to the process of adaptation.

Supportive/Nurturing Role

This theme is consistent with McCubbin & McCubbin's (1991) model of family adjustment and adaptation. This theme appears to include two of the sources of resources (a) individual family members, and (b) the family unit. The woman's role as supportive and nurturing caregiver are related to personal resources such as personality traits; physical and emotional health; a sense of mastery; and self-esteem. The second second

source of resources are family system resources which include adaptability, family organization, and communication skills.

CHAPTER 5 - SUMMARY

In recent years the family has become the focal point in the rehabilitation process for individuals with brain injuries. It is the spouse who typically carries the greatest burden of caregiving in the aftermath of a brain injury.

Sixty-two women participated in the original study (Ford, 1993). The women were interviewed briefly by telephone and were asked two open-ended questions. The qualitative statements obtained from the two-open ended questions were the focus for analysis in the present investigation.

Using concept mapping to analyze the data, resulted in the development of two cluster maps that contained ten and seven themes. Women respond to the effects of their husbands' brain injuries differently. A number of conclusions can be made, however, based on the findings of the present study:

1. In response to an open-ended question regarding the effects of their husbands' brain injuries on the women, ten themes were generated including positive attitude to self, confidence/independence, responsibilities, resentment/frustration, stress/support issues, loss issues, family adaptation, marital/communication difficulties, dependency issues, and verbal/physical abuse.

2. In response to an open-ended question on how the women dealt with the effects of their husbands' brain injuries seven themes were generated including coping

via distractions, time for self, patience/open mind, counselling/support groups, family/friends support, family cohesiveness, and supportive/nurturing role.

All of the themes which were generated from both questions under investigation, appeared to be consistent with the current literature on spousal adaptation to brain injury.

Limitations

Limitations inherent in the present study stem primarily from the inability to determine the frequency of occurrence of the resulting themes. Therefore, the themes which emerged should not be viewed as having a high frequency of occurrence.

Another bias is in the selection of subjects. A random sample would have included women whose husbands were not involved with either the Northern Alberta Brain Injury Society, the Glenrose Rehabilitation Hospital, or the Workers' Compensation Board.

Implications for Future Practice

The results of the present study indicate the critical role of the spouse in terms of rehabilitation of the individual with a brain injury. Therefore, attention to the needs of the spouse has to be emphasized if long-term outcomes are to be maximized.

The psychosocial impact of the long-term effects of a brain injury on the spouse must be recognized by health care and social service agencies. Several researchers in the area of rehabilitation from brain injuries have stressed the importance of the requirement of information to spouses and families (Lezak, 1988; Mauss-Clum & Ryan, 1981; Oddy,

Humphrey & Uttley, 1978). Jacobs (1989b) suggests that families become more effective case managers when they are provided with information and training regarding the long-term effects of brain injuries, problem identification, problem solving, and resource utilization.

Some women describe support groups as a important resource for information and social support. Several researchers have described the importance of support groups or community services for spouses and families (Brown & McCormick, 1988; Zeigler, 1989). Support groups can provide information and emotional support which may improve the spouses' ability to adapt to the new circumstances.

Concept maps are useful tools to assist mental health professionals in identifying some of the possible underlying issues clients may be dealing with. This is most helpful in the counselling situation, because the counsellor can be educated about some of the problem areas, and thereby develop intervention strategies. For example, one of the issues that some of the wives experienced was verbal and/or physical abuse. If a counsellor is aware of this possibility, then they may be more apt to ask if any abuse is occurring. Another way concept mapping can be utilized is in group counselling. Concept maps provide a clear visual representation of issues, and can be used as an aid for discussion. In individual counselling the client may or may not be dealing with the same issues; however, they can be educated about some of the common complaints and methods of coping with husbands who have a brain injury.

In conclusion, this study suggests that the wives of men with brain injuries experience difficulties in adapting to the changes in their lives as a result of their husbands' injuries. An inability to cope with the stresses of this situation may lead to marital breakdown, and/or significant personal distress. Therefore, it is essential that early in the rehabilitation process, women be provided with information and support to help them to better adapt to their circumstances. Concept maps should be included as part of the information they receive. Health care professionals need to develop a better understanding of all of the factors which might enhance the lives of these women, their husbands, and their families. In doing so, their interventions may lessen some of the burden experienced by these women and their families.

Suggested Research

Further research aimed at validating, empirically, the themes derived in the present study, either through additional qualitative research or quantitative studies is required. In addition, questionnaires can be developed from both concept maps investigating the frequency of occurrence of such themes. A rating scale could be developed as a screening instrument, which would give the clinician a clearer picture of the issues most pertinent to the client. Future research could examine the differences in concept maps between the original sample as sorters and another group as sorters. Moreover, the sorters in this study were both male and female, and there were only females in the original study. Therefore, it may be useful to conduct a study to see if there are any gender differences in sorting.

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APPENDIX A

SORTING INSTRUCTIONS

Enclosed is a list of 77 and 80 statements made by wives of husbands who have had brain injuries. The first set of 77 statements relates to the question How has your husband's brain injury affected you? The second set of 80 statements relates to the question How have you dealt with your husband's brain injury?

We are asking for your help in sorting these statements into groups which contain a common theme. You can sort the statements into as many groups as you wish. Statements can be kept separate if you don't think they fit into any group. Please do not place all the items into one pile or leave all the items to form 77 or 80 separate groups. The following example shows several statements which have been grouped together along with the theme of the group.

Example

Statements:

1. I am a good person
2. I always do my best
3. I do many things well
4. Many people like me.

Theme:

Positive view of self

To sort the statements

- A. Group the statements which you think go together.
- B. Staple each group together.
- C. Place all the groups, and any statements not sorted into a group, into the enclosed envelope.
- D. Make sure to group statements from question one and question two separately.

Thanks!

Karima Lacene

APPENDIX B
CLUSTER SOLUTIONS FOR QUESTION 1

**5 CLUSTER MAP**

5 CLUSTER SOLUTION

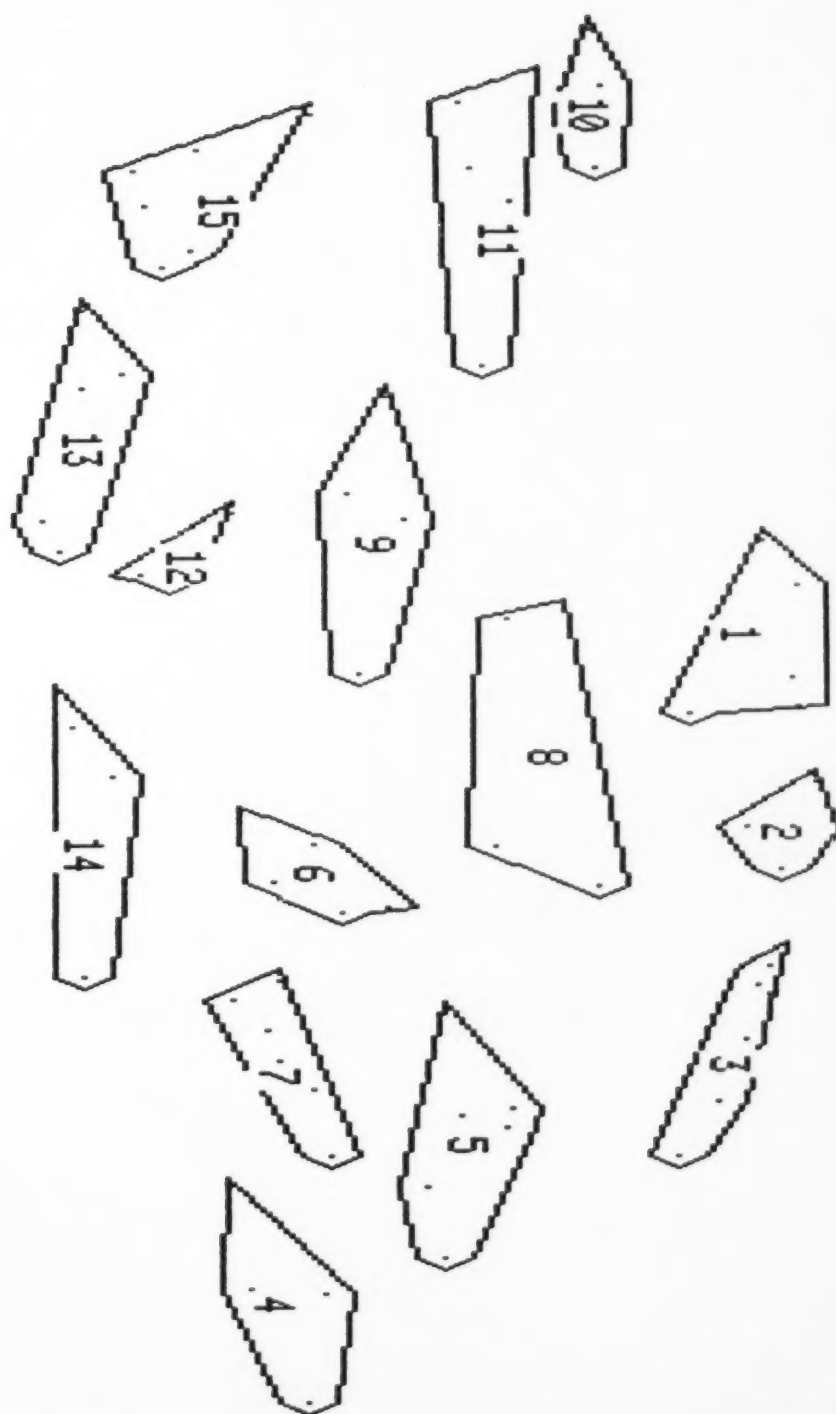
Cluster/Items	Bridging Index
Cluster #1	
I realize how much I do care for him.	0.26
I've become a more caring person.	0.20
It has made us much closer as a family.	0.60
People were kind and stood behind us.	0.54
It has taken a lot of understanding and patience.	0.55
It's made me more aware of what's important in life.	0.07
I take pride in knowing I did the very best for someone I love.	0.12
I'm no longer shy and withdrawn.	0.07
It changed my attitude toward people with injuries.	0.18
I am more independent.	0.16
I became a survivor.	0.38
It made me go back to school.	0.75
I become much stronger emotionally.	0.00
It has given me more confidence in myself.	0.07
It has made me mature, and I do things I didn't think I could do.	0.13

I've come to know the Lord.	0.09
Cluster Average	0.26
Cluster #2	
I had to take over all responsibilities.	0.70
I had to take over all decisions.	0.70
My role changed, now everything is my responsibility.	0.70
Loss of income and I'm frustrated with finances.	0.54
I'm totally responsible for his care.	0.79
I have no one to discuss decisions with.	0.70
I haven't recovered yet.	0.53
I feel guilty for resenting and disliking him.	0.45
I've given up a lot-I feel bitter.	0.43
I'm not as carefree or easygoing.	0.67
I'm a lot more judgemental and have higher expectations.	0.66
Now I work because I have to.	0.75
I'm frustrated that I can't provide for the family.	0.70
Great increase in stress level.	0.41
His being home all the time is difficult.	0.62
Lack of support medically and from social services.	0.20
I was disappointed in the little support we received from the	0.41

family.	
I need coping skills and more support.	0.27
Lots of guilt for not being as good as one could.	0.33
Before this happened I was ready to update my education.	0.59
I'm mentally/emotionally drained.	0.32
I have had a lot of sleepless nights.	0.32
I cry a lot.	0.32
It's given me some really difficult times, worries.	0.42
Cluster Average	0.52
Cluster #3	
I became very protective of him.	0.78
It hurts to see him going through this.	0.51
There are some changes, irritating, but I live with them.	0.89
I miss him.	0.75
Lost social contact.	0.62
Our sex life is down the tubes.	0.78
There is no more love, everything is gone.	0.70
When one person in the house has a brain injury everyone has it.	0.77
Cluster Average	0.72

Cluster #4	
It's been hard on the children.	0.13
The children had to grow up too fast.	0.13
He will side with the children rather than discipline them.	0.45
The kids missed out on their dad.	0.23
Family activities have declined and are at a minimum.	0.49
We've had to change our whole way of living.	0.91
I have to be the referee between him and the kids.	0.52
The family is careful not to upset him.	0.71
I couldn't leave the kids alone with him.	0.82
His health is poor, which affects the family.	0.74
Cluster Average	0.51
Cluster #5	
He is not the same person, which has indirectly affected me.	0.56
He has mood swings, which causes stress for me.	0.57
It is very hard to get along with him.	0.62
He's had growing pains.	0.49
He complains that nobody talks to or listens to him.	0.58
He's too secretive with me.	0.22
He forgets everything.	0.50

He cannot hear too well-he cannot understand me.	0.62
He was unable to assume his role as a spouse.	0.92
He leaves things sit for months.	0.86
There are a lot of things he can't do physically.	0.75
My husband seems to depend on me for everything.	1.00
He can't be caring.	0.35
He gets aggressive quickly.	0.17
He's mentally and verbally abusive.	0.40
He was very abusive both verbally and physically.	0.44
His functioning is quite variable.	0.53
Everything has to be his way.	0.47
My husband has talked about wanting out of the marriage.	0.95
Cluster Average	0.58



15 CLUSTER MAP

15 CLUSTER SOLUTION

Cluster/Items	Bridging Index
Cluster #1	
I realize how much I do care for him.	0.26
I've become a more caring person.	0.20
It has made us much closer as a family.	0.60
People were kind and stood behind us.	0.54
It has taken a lot of understanding and patience.	0.55
Cluster Average	0.43
Cluster 2	
It's made me more aware of what's important in life.	0.07
I take pride in knowing I did the very best for someone I love.	0.12
I'm no longer shy and withdrawn.	0.07
It changed my attitude toward people with injuries.	0.18
Cluster Average	0.11
Cluster # 3	
I am more independent.	0.16

I became a survivor.	0.38
It made me go back to school.	0.75
I become much stronger emotionally.	0.00
It has given me more confidence in myself.	0.07
It has made me mature, and I do things I didn't think I could do.	0.13
I've come to know the Lord.	0.09
Cluster Average	0.23
Cluster #4	
I had to take over all responsibilities.	0.70
I had to take over all decisions.	0.70
My role changed, now everything is my responsibility.	0.70
Loss of income and I'm frustrated with finances.	0.54
I'm totally responsible for his care.	0.79
I have no one to discuss decisions with.	0.70
Cluster Average	0.69
Cluster #5	
I haven't recovered yet.	0.53
I feel guilty for resenting and disliking him.	0.45
I've given up a lot-I feel bitter.	0.43

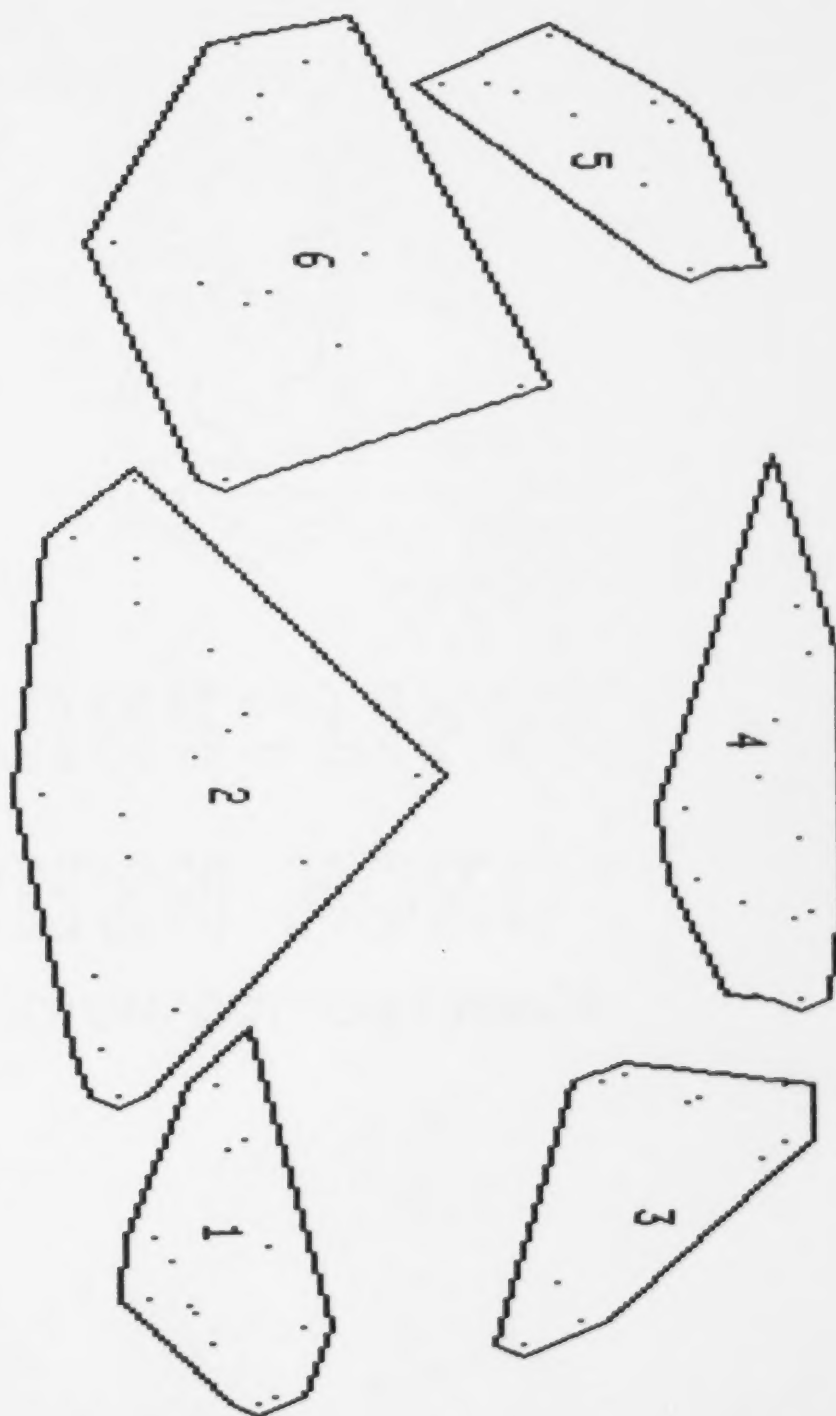
I'm not as carefree or easygoing.	0.67
I'm a lot more judgemental and have higher expectations.	0.66
Now I work because I have to.	0.75
I'm frustrated that I can't provide for the family.	0.70
Cluster Average	0.60
Cluster #6	
Great increase in stress level.	0.41
His being home all the time is difficult.	0.62
Lack of support medically and from social services.	0.20
I was disappointed in the little support we received from the family.	0.41
I need coping skills and more support.	0.27
Cluster Average	0.38
Cluster # 7	
Lots of guilt for not being as good as one could.	0.33
Before this happened I was ready to update my education.	0.59
I'm mentally/emotionally drained.	0.32
I have had a lot of sleepless nights.	0.32
I cry a lot.	0.32
It's given me some really difficult times, worries.	0.42

Cluster Average	0.38
Cluster #8	
I became very protective of him.	0.78
It hurts to see him going through this.	0.51
There are some changes, irritating, but I live with them.	0.89
I miss him.	0.75
Cluster Average	0.73
Cluster #9	
Lost social contact.	0.62
Our sex life is down the tubes.	0.78
There is no more love, everything is gone.	0.70
When one person in the house has a brain injury everyone has it.	0.77
Cluster Average	0.72
Cluster #10	
It's been hard on the children.	0.13
The children had to grow up too fast.	0.13
He will side with the children rather than discipline them.	0.45
The kids missed out on their dad.	0.23
Family activities have declined and are at a minimum.	0.49

Cluster Average	0.29
Cluster #11	
We've had to change our whole way of living.	0.91
I have to be the referee between him and the kids.	0.52
The family is careful not to upset him.	0.71
I couldn't leave the kids alone with him.	0.82
His health is poor, which affects the family.	0.74
Cluster Average	0.74
Cluster #12	
He is not the same person, which has indirectly affected me.	0.56
He has mood swings, which causes stress for me.	0.57
It is very hard to get along with him.	0.62
Cluster Average	0.58
Cluster #13	
He's had growing pains.	0.49
He complains that nobody talks to or listens to him.	0.58
He's too secretive with me.	0.22
He forgets everything.	0.50
He cannot hear too well-he cannot understand me.	0.62

Cluster Average	0.48
Cluster #14	
He was unable to assume his role as a spouse.	0.92
He leaves things sit for months.	0.86
There are a lot of things he can't do physically.	0.75
My husband seems to depend on me for everything.	1.00
Cluster Average	0.88
Cluster #15	
He can't be caring.	0.35
He gets aggressive quickly.	0.17
He's mentally and verbally abusive.	0.40
He was very abusive both verbally and physically.	0.44
His functioning is quite variable.	0.53
Everything has to be his way.	0.47
My husband has talked about wanting out of the marriage.	0.95
Cluster Average	0.47

APPENDIX C
CLUSTER SOLUTIONS FOR QUESTION 2



6 CLUSTER MAP

Cluster Items and Bridging Values for Concept Map of "How have you dealt with your husband's brain injury?"

6 CLUSTER SOLUTION

Cluster/Items	Bridging Index
Cluster #1	
I do a lot of reading.	0.28
I keep a journal.	0.22
I've become involved in volunteer work.	0.24
I went back to school, took upgrading.	0.49
Sometimes I escape by going to sleep.	0.08
I use medications.	0.05
I go to work; it's my escape.	0.26
I walk a lot.	0.07
Sometimes I go for a drive to get peace of mind.	0.00
I keep busy and find things to do: ie. crafts, curling.	0.03
I've done a lot of talking to myself-to cope.	0.20
I cried a lot.	0.26
I try not to get terribly depressed.	0.26

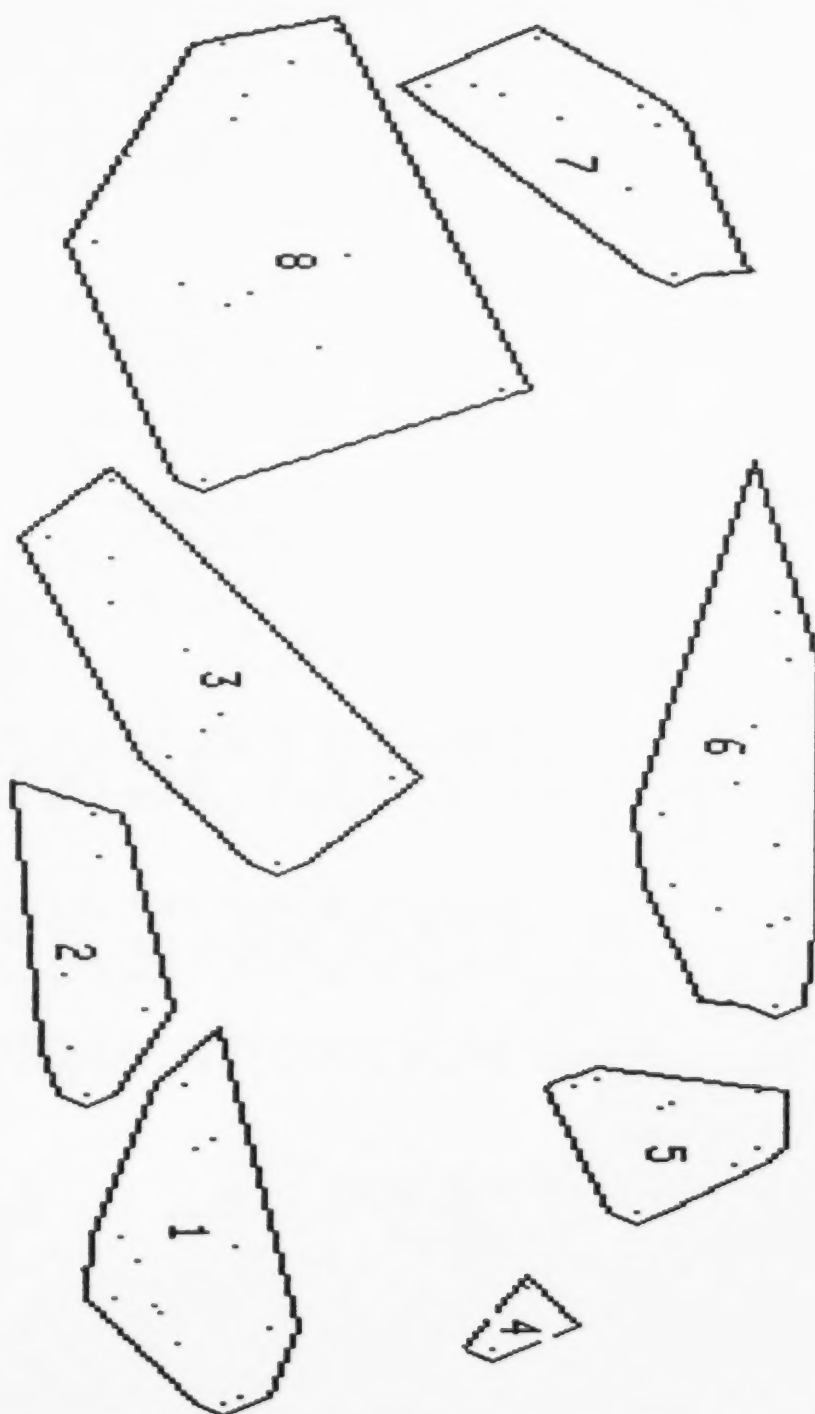
I try to keep problems to myself.	0.34
I go on a little shopping spree-it's just a little lift.	0.00
Cluster Average	0.19
Cluster # 2	
I've learned to live with it.	0.41
I try to stay calm.	0.32
Knowing how fast time goes by.	0.80
I take one day at a time, and I give myself time.	0.27
Sometimes I just tune him out.	0.28
My time is mine.	0.22
A lot of times I tend to forget about it.	0.33
I look for the good that happened that day.	0.54
I have a lot of patience.	0.49
I've kept an open mind.	0.48
I try not to be bitter or selfish.	0.62
I had to overcome my belief that I could "do it all".	0.63
I find a solution and deal with it.	0.60
I had to change my standards.	0.41
I've learned to adjust myself to his moods.	0.52
I had to learn to put my foot down, to be assertive.	0.63

I have adjusted time schedules, and dropped activities in order to accommodate the changes.	0.95
Cluster Average	0.50
Cluster #3	
I attend counselling.	0.71
Moving to a smaller town was helpful.	1.00
I listen to a particular family program.	0.83
I hope that there would be help.	0.55
I got funding.	0.76
I went to a NABIS meeting.	0.41
We're very aware of support groups but don't use them.	0.88
I talked to our family doctor about it.	0.24
Career Connectors in our small town have given me some help.	0.25
I've talked to doctors-family physician, psychologist, and specialist.	0.08
I began a brain injury support group.	0.63
Cluster Average	0.58
Cluster #4	
I have contact with friends.	0.54
I've taken him to various doctors and professionals.	0.63

My husband and I sought marital and family counselling.	0.41
Initially I had homecare, but it's an intrusion.	0.45
My husband's company has been ace.	0.40
Our church and my faith has been a big support.	0.19
We moved back to the city to facilitate my employment and better medical attention for my husband.	0.69
Learning about it from the library and from professionals was helpful.	0.23
My husband attends counselling.	0.26
We have a good family doctor who listened and gave advice.	0.13
I've had support from family.	0.38
Everyone around me was supportive.	0.32
The kids were and are a tremendous support for me.	0.53
Cluster Average	0.40
Cluster #5	
It helped me to see the kids handle it so well.	0.63
I accept they (the family) can't do everything.	0.69
As a family we're extremely open about talking and laughing about it (the brain injury).	0.23
Teasing and joking about it works well for us as a family.	0.24

My husband and I have a real sense of family.	0.37
I would never consider leaving him.	0.60
We talk about it-we have good communication.	0.50
We try to do things socially together- like movies.	0.41
We tried to keep as normal as life as possible.	0.58
I love my husband and its important that we stay together as a family.	0.40
Sometimes we've stayed away from people in order to have time alone.	0.87
Cluster Average	0.50
Cluster #6	
I try to understand and keep accepting the way he is.	0.63
I'm grateful for every little improvement.	0.83
I had some problems to get him to go out and communicate with others.	0.65
I overlooked many things-not his fault.	0.59
I need to wean him (from me) he's very demanding.	0.92
I don't want to put negative feelings against my husband with my family.	0.97
I was very supportive of him.	0.66

I think it takes more work to work things out.	0.78
I spent a lot of time at the hospital with my husband.	0.52
I deal with him as I would my teenage sons.	0.78
I can calm him down.	0.49
I had to simplify a lot of things for him-to explain routines.	0.44
I try to help him remember things and keep his brain active.	0.45
Cluster Average	0.67



8 CLUSTER MAP

8 CLUSTER SOLUTION

Cluster/Items	Bridging Index
Cluster #1	
I do a lot of reading.	0.28
I keep a journal.	0.22
I've become involved in volunteer work.	0.24
I went back to school, took upgrading.	0.49
Sometimes I escape by going to sleep.	0.08
I use medications.	0.05
I go to work; it's my escape.	0.26
I walk a lot.	0.07
Sometimes I go for a drive to get peace of mind.	0.00
I keep busy and find things to do: ie. crafts, curling.	0.03
I've done a lot of talking to myself-to cope.	0.20
I cried a lot.	0.26
I try not to get terribly depressed.	0.26
I try to keep problems to myself.	0.34
I go on a little shopping spree-it's just a little lift.	0.00

Cluster Average	0.19
Cluster # 2	
I've learned to live with it.	0.41
I try to stay calm.	0.32
Knowing how fast time goes by.	0.80
I take one day at a time, and I give myself time.	0.27
Sometimes I just tune him out.	0.28
My time is mine.	0.22
A lot of times I tend to forget about it.	0.33
Cluster Average	0.38
Cluster #3	
I look for the good that happened that day.	0.54
I have a lot of patience.	0.49
I've kept an open mind.	0.48
I try not to be bitter or selfish.	0.62
I had to overcome my belief that I could "do it all".	0.63
I find a solution and deal with it.	0.60
I had to change my standards.	0.41
I've learned to adjust myself to his moods.	0.52
I had to learn to put my foot down, to be assertive.	0.63

I have adjusted time schedules, and dropped activities in order to accommodate the changes.	0.95
Cluster Average	0.59
Cluster #4	
I attend counselling.	0.71
Moving to a smaller town was helpful.	1.00
I listen to a particular family program.	0.83
Cluster Average	0.85
Cluster #5	
I hope that there would be help.	0.55
I got funding.	0.76
I went to a NABIS meeting.	0.41
We're very aware of support groups but don't use them.	0.88
I talked to our family doctor about it.	0.24
Career Connectors in our small town have given me some help.	0.25
I've talked to doctors-family physician, psychologist, and specialist.	0.08
I began a brain injury support group.	0.63
Cluster Average	0.47

Cluster #6	
I have contact with friends.	0.54
I've taken him to various doctors and professionals.	0.63
My husband and I sought marital and family counselling.	0.41
Initially I had homecare, but it's an intrusion.	0.45
My husband's company has been ace.	0.40
Our church and my faith has been a big support.	0.19
We moved back to the city to facilitate my employment and better medical attention for my husband.	0.69
Learning about it from the library and from professionals was helpful.	0.23
My husband attends counselling.	0.26
We have a good family doctor who listened and gave advice.	0.13
I've had support from family.	0.38
Everyone around me was supportive.	0.32
The kids were and are a tremendous support for me.	0.53
Cluster Average	0.40
Cluster #7	
It helped me to see the kids handle it so well.	0.63

I accept they (the family) can't do everything.	0.69
As a family we're extremely open about talking and laughing about it (the brain injury).	0.23
Teasing and joking about it works well for us as a family.	0.24
My husband and I have a real sense of family.	0.37
I would never consider leaving him.	0.60
We talk about it-we have good communication.	0.50
We try to do things socially together- like movies.	0.41
We tried to keep as normal as life as possible.	0.58
I love my husband and its important that we stay together as a family.	0.40
Sometimes we've stayed away from people in order to have time alone.	0.87
Cluster Average	0.50
Cluster #8	
I try to understand and keep accepting the way he is.	0.63
I'm grateful for every little improvement.	0.83
I had some problems to get him to go out and communicate with others.	0.65
I overlooked many things-not his fault.	0.59

I need to wean him (from me) he's very demanding.	0.92
I don't want to put negative feelings against my husband with my family.	0.97
I was very supportive of him.	0.66
I think it takes more work to work things out.	0.78
I spent a lot of time at the hospital with my husband.	0.52
I deal with him as I would my teenage sons.	0.78
I can calm him down.	0.49
I had to simplify a lot of things for him-to explain routines.	0.44
I try to help him remember things and keep his brain active.	0.45
Cluster Average	0.67